

Intergenerational, integrative and intellectual Pacific properties and pathways for life (IPforLife): a study protocol

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ABSTRACT

Introduction. Chronic disease such as cancer, cardiovascular, diabetes, mental health and obesity have debilitating effects on sufferers with impacts seen increasingly at a younger age. A whole-of-family approach to life-course research is essential to inform health and wellbeing policies and programmes that make a difference for children, youth, adults, and later in life. **Aim.** The aim is to present the research protocol about a study to understand the impact of chronic conditions on families, with an emphasis on outcomes that have life-long benefits, and co-develop a sustainable and culturally centred life-course programme for overall health and wellbeing. **Methods.** The qualitative study will assess the family, household and community strengths that allow people in the Tokelau community to thrive despite the challenges of living in households with chronic disease. A total of 200 participants will be involved in family group and stakeholder focus group interviews, digital storytelling and community-based participatory action workshops, and the implementation and evaluation of action plans. The study will be augmented by Pacific research models, and the New Zealand Health Research Council Pacific guidelines. **Results.** Research findings will have implications for policy and primary health-care delivery, and the potential to upscale and construct life-enhancing pathways across the life-course. **Discussion.** Understanding Tokelauan families' health status, exposure to health hazards, access to health services and medicines, and the strengths of the family unit and community that allows them to thrive despite the challenges of living with chronic conditions, can help to inform policy and practice, and achieve better health outcomes for them.

Keywords: chronic disease management, chronic disease, family health care, life-course, Pacific communities, Pacific families, primary health care.

Introduction

Chronic disease such as cancer, cardiovascular, diabetes, mental health and obesity have a direct effect on the life-course, with impacts seen increasingly at a younger age. The indirect effect of chronic disease on the family has been less well-studied and is likely to also have impacts across the entire life-course. Research that does exist highlights the health impact on caregiving for a chronic disease sufferer^{1–4} and the long-term impact on children who live with parents with mental health problems.^{5,6} Less is known about the impact of chronic conditions on the economic functioning of the family and household, on different family members, and across different family types and generations. By taking a life-course approach to inform future health and wellbeing policies and programmes, the Intergenerational, integrative and intellectual Pacific properties and pathways for life (IPforLife) study will apply a formative and multidisciplinary approach⁷ to understand the factors that impact different stages of the life-course, and assess the family, household and strengths that allow Pacific Peoples to thrive despite the challenges of living with chronic disease.

Pacific Peoples are disproportionately represented in the lower socio-economic strata. A strong correlate exists between low socio-economic strata communities and compromised health.^{8,9} Although complex in causality,¹⁰ the consequences are evident in

WHAT GAP THIS FILLS

What is already known: Chronic disease such as cancer, cardiovascular, diabetes, mental health and obesity have debilitating effects on sufferers.

What this study adds: Far less is known about the indirect effects of chronic disease on the family. We describe the protocol for a qualitative study to investigate the impact of chronic conditions on families and understand the outcomes that have life-long consequences. The study will create new methods that can be applied for examining the context of health and wellbeing across the life-course.

disproportionate poor health and wellbeing statistics, low representation in higher socio-economic status occupations, and intergenerational cycles of disadvantage – physically, financially, educationally, emotionally, and socially.

According to the 2018 census, Pacific Peoples are the fourth largest ethnic group at 8.1% (381,642) of the total New Zealand population.^{11,12} The Pacific population is diverse, highly urbanised, and growing rapidly, with a median age of 23 years and 34% aged <15 years compared with 5% aged over 65 years.¹¹⁻¹³ The youthful Pacific population provides a high ‘demographic dividend’ for all health and wellbeing actions that can impact the life-course due to the large proportion of the population at the early stages of life. Moreover, Pacific Peoples have a holistic view of health and wellbeing and play a central role in the community to affirm their identity and support.^{13,14} Of the total Pacific population in New Zealand, the majority are Samoan (47.9%), followed by Tongan (21.6%), Cook Island Māori (21.1%), Niuean (8.1%), Fijian (5.2%), Other Pacific Peoples (3.9%) and Tokelauan (2.3%).

Justification

Accurate data are essential to inform policy and practice; however, this is often unavailable for small populations, although these groups experience significant health inequities ‘making it an ethical imperative to explore and implement solutions to the problem of inaccurate data’.¹⁵ As former President Obama of the United States of America put it, ‘Smaller communities in particular can get lost, their needs and concerns buried in a spreadsheet’.¹⁶ The paucity of data, or lack thereof, means that these small population groups are often overlooked, resulting in missed opportunities to inform solutions to the burgeoning inequities they face.¹⁷ Equity recognises the need for fair and proportionate service delivery to address the challenges we face and that different people with different levels of advantage require different approaches to achieve better equitable health and wellbeing outcomes.^{18,19}

Our commitment to small communities whose voices have been missing from critical dialogue also reflects Pacific community preferences for ethnic-specific research to achieve meaningful and sustainable outcomes. Chronic conditions such as diabetes and obesity rate among the health disparities Pacific Peoples face in New Zealand.²⁰ In 2016, Tokelau was ranked at #1 of the top 10 diabetes-prevalent countries in the world.²¹ Pervasive and enduring engagement with the Tokelau community is needed if we are to achieve better outcomes for them.

Approximately 8700 Tokelauans live in New Zealand; 48% in Wellington and 28% in Auckland.¹¹ Seventy-nine percent of Tokelauans are New Zealand-born, the third highest among Pacific ethnic groups in New Zealand. They are well networked and have the potential to lay the groundwork for insights into the strengths and resilience that support their sufferers of chronic disease. Tokelau is a realm state of New Zealand, which provides Tokelauans with dual citizenship and the freedom of passage between Tokelau and New Zealand. This is important as the imminent portability of the National Health Index (NHI) number for Pacific realm nations (Tokelau, Cook Islands, Niue) will enable future life-course research that includes the frequent return migration between New Zealand and the realm nations. Doing this study now with the Tokelau community will help to inform the monitoring of health and wellbeing outcomes that the shared NHI numbers will enable.

Tokelauans have also collaborated generously with researchers by sharing their time, lived experiences and indigenous knowledges.^{22,23} The Tokelau Migrant Study conducted approximately 50 years ago²⁴ was a world leading multi-disciplinary project that is regarded as one of the most prominent examples of population context epidemiology during the ‘modern epidemiology’ era.²⁵ The IPforLife study will enable historic comparisons and create culturally imbued methods to examine the contemporary context of health and wellbeing across the life-course. For this initiative to be successful in the long term, the priority issues to be addressed must be identified by the community themselves. This protocol outlines our proposed research with the Tokelau community.

Aim

The aim of this article is to present the research protocol about a study to understand the impact of chronic conditions on families and the outcomes that have life-long consequences; and co-develop a sustainable and culturally centred life-course programme for overall health and wellbeing outcomes in the Tokelau community. We will:

1. build on the results of the sister study using administrative data from the Integrated Data Infrastructure (IDI)²⁶ to define the New Zealand population cohort, identify the

- number of families with chronic condition sufferers, and assess outcomes; and
- investigate family and community views on health and wellbeing across the life-span to identify their cultural beliefs, values, and perspectives to inform relevant policy and services across the social, health and economic spectrum.

Research question

The overarching question is: How can meaningful engagement and participation in life-course research lead to family and community health and wellbeing? We will seek to understand what Tokelauans interpret as ‘meaningful engagement and participation throughout the life-course’ in the context of their own lives and personal experiences, and perspectives on ‘healthy bodies, minds, lives and behaviours’ in relation to their age and role in the family, community, workplace, and school. We will also seek to understand the strengths that allow them to thrive despite the challenges of living in households with chronic disease.

Methods

The IPforLife study is a qualitative study that is presented in this research protocol. The study will align with a quantitative sister study using administrative data from the IDI, a collection of linked data sources on health, social services, education, employment and socio-economic wellbeing.

Research sites

The research sites for the study are Auckland and Wellington where the majority of Tokelauans live.

Participants

Participants will be recruited to identify and initiate solutions to addressing what matters to them in relation to the impact of chronic disease across the life-course. They will be recruited by purposeful sampling²⁷ through our collaborators and Reference Group. The primary health-care collaborators, Tongan Health Society in Auckland and Pacific Health Plus in Wellington, were subcontracted to the study in December 2020. A Reference Group of seven senior Tokelauan leaders was established under a memorandum of understanding with the University of Auckland in May 2021.

Our previous research with Pacific communities leads us to estimate that a total of 60 family members from 12 family group interviews will enable detailed insight into participant experiences across the life-span. Approximately 36 key stakeholders from six focus groups will also provide a diversity of perspectives and experiences. Two digital storytelling workshops (DST) are planned for up to six households who take part in the family group interviews, and approximately 120 participants are expected to attend the 12 community-

based participatory action research workshops. These events will be fully catered for the participants; they will also receive petrol or food vouchers for their contributions to the research. Participants will also be invited to choose the venue for their interview or workshop. For example, participants in a family group may choose to be interviewed at home, whereas participants to a local community workshop may choose their own church hall or community hall for convenience. Return transport to attend an interview or workshop will be provided, as required.

Interviews

Face-to-face in-depth family group and stakeholder focus group interviews will be centred around five topics: (1) Experiences in a household with a family member(s) living with a chronic disease, and barriers and enablers to optimising the individual and family roles within the household; (2) Unmet physical and psycho-social needs of the family, the way they engage with the community and social and health services, and the barriers to meaningful engagement and participation; (3) Satisfaction with and appropriateness of publicly funded services, and the extent to which they feel supported in their daily lives and the value they place on different interactions; (4) Extent to which the expressed priorities of the family were met and the significance of intergenerational living patterns and relationships; and (5) Ways in which families living in a household with a chronic disease and extended family and the wider community can be supported. Other relevant topics emerging from the interviews may be added. A family group will comprise the family in a household with at least one member with a chronic health condition. A stakeholder focus group will comprise participants from key sectors (e.g. health, education, social services, non-governmental organisations, and community leadership groups).

Workshops

Participants in the digital storytelling workshops will have the opportunity to create 3- to 5-min visual narratives that ‘synthesise images, video, audio and text to create compelling accounts of experiences’.²⁸ The socially based approach posits community engagement as the story centre to meaningfully capture participants’ lived experiences in an engaging manner.^{28,29} These workshops also allow participants and users to elicit nuanced meaning that may otherwise be unreachable for diverse audiences.³⁰ The collective and systematic enquiry is designed to improve practice or effect social change³¹ and is currently practiced in a myriad of locations to produce short videos as educational and learning tools.³² Digital storytelling can elucidate rich narrative data to ‘harness the communicative power of digital technology and facilitate the creation and sharing of stories with a worldwide audience’,³³ as well as strengthen connections in cultures and values, and highlight issues for advocacy.³⁴ Researchers in

Auckland adapted the method to include Māori cultural protocols as part of their palliative care study.³⁵ Dewes also conceptualised the digital storytelling method to be culturally appropriate for a study with Pacific family carers.⁴

Participants in the community-based³¹ workshops will be engaged to discuss their experiences, investigate the impact of chronic conditions on families, identify the strategies they need to embed in their interventions, and evaluate the activities they develop and implement for themselves. The structure and design of these workshops will be determined by the participants in consultation with the Reference Group and will be guided through an action–reflection cyclical process in four phases.

Phase 1: issue identification and clarification

Administrative data collected from the quantitative sister study will be presented to guide further exploration of the underlying drivers and cultural explanations of engagement within the family and community. Issues identified by the participants with the research team will reinforce the foundation for the study and is reliant upon the participants sharing their knowledge and expertise in developing measurable and achievable outcomes. A shared understanding of priority issues will be developed in this phase to identify and clarify the research pathways for the following phases.

Phase 2: knowledge-sharing

Using Pacific research models,^{36–42} an exploration of the underlying drivers and cultural explanations of engagement within the family, culture, and the community will be further explored in this phase to define the strengths, challenges and opportunities for household members living with family with a chronic disease. Talanoa^{37,38} is interactive and allows participants to articulate their experiences in their own voice and preferred language with the assistance of an interpreter, as required. The over-arching research question will guide the participants' cultural considerations, from a Tokelauan perspective, in the context of their own lives and personal experiences.

Phase 3: solution-building

The strengths, challenges and opportunities for household members living with family with a chronic disease will be further defined in this phase through an action–reflection cyclical process of issue identification, clarification, and solution-building. This will be a process of ongoing talanoa to inform the next phase of the study by affirming the key themes and solutions derived from the narrative⁴³ and thematic⁴⁴ analyses of the data.

Phase 4: implementation, evaluation and nurturing the change

This phase will focus on implementing the solutions and action plans, and evaluation of the uptake and outcomes in

the community. A preliminary analysis of the data will be undertaken by the research team in consultation with the Reference Group and taken back to each group for review before developing the action steps. These steps and interventions for implementation and evaluation will be based on the themes identified by the participants. Data will be coded and analysed using narrative and thematic analyses and will incorporate the Pacific health models selected for this study. The evaluation will be analysed using an inductive approach.⁴⁵

Pacific health models

The research will be augmented by the Tokelau health model, Te Vaka Atafaga,³⁶ the Pacific oral tradition of talanoa,^{37,38} and the New Zealand Health Research Council (HRC) guidelines for conducting research with Pacific Peoples,³⁹ to create and maintain authentic engagement with the Tokelau community. Te Vaka Atafaga comprises six components that will be integral to the research and 'total wellbeing of the Tokelau person within the context of the extended family': (1) Physical body; (2) Mind; (3) Family; (4) Spirituality and belief systems; (5) Environment; and (6) Social and support systems.³⁶ Talanoa is a Pacific concept for open dialogue that has been applied in critical discussions and conversations in a variety of settings.^{37,38,40–42} The study will adhere to talanoa protocols of respect, kindness, cultural competency and empathy.^{37,38} The HRC guidelines³⁹ underpin the following Pacific cultural values and beliefs in the IP4Life study: communal relationships, reciprocity, holism, cultural sensitivity, and respect.

Analysis and dissemination

Interviews will be recorded with permission and transcribed. Transcripts will be analysed and informed by Pacific research protocols and frameworks using narrative⁴³ and thematic⁴⁴ analyses within specific domains with the aid of nVivo 10 (QSR International), a qualitative data analysis software tool. Following preliminary analysis of the data, feedback will be provided to the participating groups for review to ensure transparency and understanding of the data before developing the action steps and interventions for implementation and evaluation. An inductive approach will be used to analyse the evaluation data.⁴⁵ Dissemination of the study protocol through this Journal is integral to our research partnerships and open communication to identify enablers and barriers, and provides empirical support for interventions that create opportunities for community ownership and leadership of sustainable health and wellbeing outcomes.

Ethics

Ethics approval for the IPforLife study, reference UAHPEC 23392, was received from the University of Auckland Human Participants Ethics Committee on 29 October 2021 for a period of 3 years. Approval for the quantitative

research has been obtained under Statistics New Zealand's confidentiality and security protocols and the University of Auckland Ethics Committee, reference AHREC 21563.

Results

Final results will be disseminated to a wide range of stakeholders and end-user organisations, including to the Tokelau families and communities. We will also consult with key stakeholders and policymakers to help drive the uptake and utilisation of our research results into practical evidence-based changes to current practices. The findings will have implications for policy and primary health-care delivery, and the potential to upscale and construct life-enhancing pathways across the life-course.

Discussion

Understanding Tokelauan families' health status, exposure to health hazards, access to health services and medicines, and the strengths of the family unit and community that allows them to thrive despite the challenges of living with chronic conditions, can help us to inform policy and practice, and achieve better health outcomes for them. To do this effectively, we propose a culturally appropriate and in-depth and transformative research process that is described in this protocol. The process will enable the Tokelauan community to define their experiences, identify solutions to the challenges they face, and implement those solutions through informed and agreed action. This approach will empower the local community to build capacity and exercise leadership over the change they want to create and maintain for themselves. Te Vaka Atafanga and talanoa research models will be applied alongside the HRC Pacific research guidelines to foster open dialogue and authentic engagement with the Tokelau community throughout the duration of the project.

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Data availability. The data generated by the research will be shared, as appropriate, upon reasonable request to the corresponding author.

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