Understanding depression in Tokelauan people in New Zealand

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BACKGROUND: The Tokelauan language lacks a word for 'depression' and this can make diagnosing and treating depression in Tokelauan patients difficult for general practitioners.

AIMS: To describe the experience of depression in Tokelauans and thereby assist diagnosis and treatment of the illness.

METHOD: Ten semi-structured in-depth interviews were conducted. The transcripts were thematically analysed using an immersion crystallisation technique.

RESULTS: An illness involving profound sadness exists in the Tokelauan culture. Tokelauans recognise isolation and withdrawal from family and community activities as indicators of extreme sadness. Privacy and pride are important cultural characteristics, which may be barriers to recognising sadness. Often the smiling Tokelauan face becomes the mask hiding sadness.

CONCLUSION: This research demonstrates the complexity of relationships between patients, their illness and their culture, that impacts on how depression manifests. This research indicates that therapy must have a whole person approach involving family, church, community and patients' spiritual beliefs.

KEYWORDS: Depression; Pacific health

Introduction

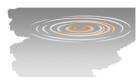
The diagnosis and management of depression in general practice is often complex. How patients present to the world can hide emotional distress; sometimes it can be difficult to see behind patients' 'masks'. If doctor and patient also struggle to bridge a socio-cultural divide, patients' illness may remain hidden and untreated.

In 2013, the Tokelauan population in New Zealand was 7176, ¹ 2.4% of the country's Pacific population of 295 941. The stimulus for this study was the observation by author IL that few of his Tokelauan patients ever presented with clinical signs of depression. He became curious about whether Tokelauans recognised, within their cultural repertoire, an illness equivalent to the western biomedical term 'depression'. This led

to the research questions: what is a comparable illness? What are its symptoms? What barriers prevent recognition? What causes it? How should doctors manage the care of Tokelauans with depression?

The only depression prevalence data that considers Pacific people as a group comes from the New Zealand Mental Health Survey² (NZMHS), although it does not specifically distinguish Tokelauans. The 2003–2004 NZMHS indicated that mental illness prevalence in Pacific people was higher than for other New Zealanders. Using the World Health Organisation's Composite International Diagnostic Interview scale³ the NZMHS showed mental illness prevalence of 29.5% for Māori and 24.4% for Pacific people, compared with 19.3% for other New Zealanders. Pacific





VAIKOLOA

Pacific Primary
Health Care
Treasures

Vai (water) is a symbol of 'life-source' and koloa (treasures) to share

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WHAT GAP THIS FILLS

What is already known: Pacific people living in New Zealand are less frequently diagnosed with depression than the general population.

What this study adds: This study contributes to general practitioners' ability to recognise and better manage depression in their Tokelauan patients and has implications for the wider Pacific population of New Zealand.

people's mental health services use was 1.8% compared with 2.2% for the general population, and only 25% of Pacific people with severe disorders used mental health services compared with 58% of other people.

The lifetime prevalence of major depressive disorder at 10.5% for Pacific people was lower than for the total population (16%), as was the 12 month prevalence (4.9% compared with 5.6%). Pacific people born in New Zealand had double the rate of depression of those who lived their first 18 years in the islands, suggesting that socio-cultural factors may be protective against depression development.

Only 1.8% of New Zealand doctors identify as ethnically Pacific,4 and only one quarter of these are general practitioners so most Pacific patients must initially consult with a doctor of different ethnicity, who may lack the cultural competence to identify their depression and manage care appropriately. Guidance to doctors in the 2005 Ministry of Health Pacific Island Mental Health Profile⁵ recognises the importance of an holistic approach to mental health in Pacific people, with treatment focusing on restoration of harmony throughout people's lives; spiritually, physically, emotionally and within families. Not all Pacific people share the same cultural mores, but there is very little depression-related research that investigates differences between Pacific ethnicities. We could find no published research on depression in Tokelauans.

Methods

We used a qualitative design with purposive sampling and one-to-one face-to-face in depth

semi-structured interviews. Initially the project was to be conducted with the Taupo Tokelauan community, but it was expanded into Auckland to include participants who had recently arrived in New Zealand. Key to this research was securing the advice, approval and participation of the Tokelauan community to recruit participants, and ensure that the research was conducted sensitively and produced results of benefit to participants and their community.6 A steering committee of two men and one woman from the Taupo Tokelauan community guided the early phases of the research, including holding two community meetings explaining the research, shaping the questions and taking responsibility for recruiting participants. The steering committee also facilitated meeting an Auckland-based Tokelauan minister and researcher who helped find participants in that region.

All participants were provided with an information sheet, offered reimbursement for interview-related travel, signed a consent form and were given the opportunity to bring a support person to the interview. Participants were informed before the interview that mental health support was available if they required it.

Interviews were conducted in a neutral setting or in participants' homes and were recorded and transcribed. The questions forming the basis of the interview are listed in Box 1.

Interviews continued until no new themes emerged. This was achieved after 10 interviews that included 14 participants: one interview included a husband and wife, and on a further occasion, an elderly Tokelauan man who spoke no English was interviewed with two younger women and a man. Transcripts were returned to participants for their review and further comment. The resulting transcripts were then analysed thematically by reading and re-reading, searching for themes and subthemes⁷ using a pragmatic approach. The result was a thematic analysis consistent with the principles of Immersion Crystallisation, ⁸ Template-Based Analysis, ⁹ and General Inductive Analysis. ¹⁰

The Northern Y Ethics Committee Ethics approved the study (No. NTY/11/06/066).

Results

Participants included 7 men and 7 women, with ages ranging from 25–65 years. Their time spent resident in New Zealand ranged from 1 month to 61 years.

Thematic analysis

Participants indicated that although the Tokelauan language does not have a word equivalent to the biomedical term 'depression', an illness equivalent to depression does exist; it has recognisable symptoms and signs of an illness that is characterised by extreme sadness. Other themes were: Tokelauans hide sadness, often behind the mask of a smiling face; cultural changes with resultant socioeconomic difficulties are the main causes of profound sadness; the family, the community and the church are all important in the management of the Tokelauan with extreme sadness; and there are recognisable signs of recovery.

'Extreme sadness' – a condition equivalent to depression

Most participants indicated that Tokelauans can experience an illness equivalent to the 'palagi' diagnosis of depression, despite being clear that there is no word for it in their language.

I am sure there is illness like that in the Tokelauan culture. As we live here in New Zealand, we have seen comparing our people to the palagi people and I am sure there is an illness like that in our culture. (Female 60+ years, long term immigrant)

You can see especially the young ones and some old people, like they got that depression but we got no word for that. (Female 30–40 years, recent immigrant)

Participants were clear that mostly sadness was just a part of life and they described it as 'unwellness' similar to any other sickness. However, they recognised a more severe condition where the

BOX 1. Interview guide

- In your language you say fakenoanoa or having sadness, and he fiafia, or he is unhappy.
 Sometimes a palagi can become so very very sad that it becomes an illness. Sometimes the sadness can become too much to bear and life does not seem worth living.
 - Is there an illness like that in the Tokelauan culture?
 - Does it have a name?
- 2. If there was someone in the family with that illness or getting it, how would you know?
- 3. If there was someone in the family with that illness, how would you deal with it?
- 4. How do people get this illness?
- 5. If someone is sad, how can you make him or her well?
- 6. How do you know when so meone is well again?
- 7. What advice would you give to someone who had recently arrived in New Zealand so they can stay well?
- 8. How might a newcomer cope with feelings of sadness?
- 9. Do women cope or deal with feelings of sadness differently from men?

sadness did not improve and this was likened to fatigue or an exhausting burden.

The symptoms and signs of depression in the Tokelauan culture - isolation and sadness

Because Tokelauan life revolves around family and community, isolation becomes a readily recognisable symptom of depression. Although Tokelauans might experience disturbed sleep, loss of motivation, irritability and loss of appetite, the symptoms of isolation and withdrawal from family and community life along with pervasive sadness are important indicators of depression.

Participants spoke of depressed people shutting themselves in their house or room, physically, or emotionally withdrawing from their immediate family, and from community engagement.

When I am feeling down I just lock myself in my room, tell everyone I am not home or just don't answer the phone. (Female 20–30 years, long term immigrant)

We laugh and share, you know, but ... when you don't see a person who usually goes to the hall for those gathering, that they don't feel like coming to the hall anymore. (Female 60+ years, long term immigrant)

It makes people down-hearted, withdrawn, lose weight, lose sense... (Male 40–50 years, established immigrant)

I can't sleep and in the morning I don't want to get up. (Female 20–30 years, long term immigrant)

Very quiet, very quiet. Doesn't say much and sometimes is a bit teary. (Male 50–60 years, long term immigrant)

Other behavioural changes included talking to oneself and, especially in men, increased frustration, alcohol use and occasionally violence.

She would be just sitting there and then all of a sudden mutter under her breath like she was talking to someone else. (Female 40–50 years, long term immigrant)

It is not many of us but we do have people you know when they sad they go to a bottle aye? (Male 50–60 years, long term immigrant)

... or having a beer or drinking and then he always causing a lot of trouble, damaging the hall or having a fight. (Male 50–60 years, long term immigrant)

Keeping it hidden; the mask of the smiling Tokelauan

Participants said that even for Tokelauans, signs of intense sadness could be difficult to recognise because cultural mores kept them hidden. Participants described pride and privacy as important values that resulted in internalising feelings and emotions.

So if I kept something inside me, people don't know that I got problems and ... things going on in my life unless I let them know and if I don't want someone to know what is going on in my life, why should I? (Female 30–40 years, recent immigrant)

The Tokelauan value on privacy could result in depressed patients feeling isolated from their family and community:

I just can't say to anybody oh I feel sad today, you know. And they don't even know that I am sad. In

my own self I just keep it to myself. (Male 50–60 years, long term immigrant)

That's why it is so hard for us to see the sign of somebody being depressed because they hide their feelings most of the time. (Male 50–60 years, long term immigrant)

One participant recalled a situation where community members did not realise someone was sad and never suspected that the subsequent suicide was a possibility.

But they said 'I wonder why his behaviour was starting to be like that? Oh that was why'. ...He was probably trying to tell us something.... They never saw those signs. (Male 50–60 years, long-term immigrant)

Participants commented that smiling was an important cultural more, learned from childhood and associated with politeness and courtesy. Smiling could also act as a mask, disguising someone's real underlying emotions and making it difficult to recognise depression.

Tokelau people always like smile and ... they sometimes pretend like, they have to smile every time so people can see everything is alright. (Female 30–40 years, recent immigrant)

Being brought up as a Tokelauan, the way your parents say stuff like, to be happy all the time ... (Female 30–40 years, established immigrant)

However, some participants noted that it was possible to recognise a false smile.

In our culture we can know, we say things to make other people laugh. We talk and laugh and – but some people they laugh together with us but you can tell by the look on their face there is something wrong. (Female 60+ years, long term immigrant)

Nonetheless, combined with placing a high value on privacy and on presenting a happy face to the world, the mask of smiling emerged as an important barrier to recognising depression, even for people close to patients.

Causes of depression in the Tokelauan culture

Participants located causes of intense sadness within the context of profound cultural upheaval. An idealised image of a carefree life in a subsistence economy was juxtaposed with pressures of living in a capitalist economy based on monetary values and working for pay: the differing cultural expectations of Tokelauan and palagi societies. Many participants described Tokelau as a country where life was worry-free. Food was free and people had no financial concerns. It was a community where everybody knew and cared for one another.

In Tokelau you don't have to worry about anything. You survive on whatever you can get on the island. You don't need to worry about money. Everything is there for you. You can get whatever you want without worrying about tomorrow – oh how can I feed my children? How can I pay the bill? (Female 60+ years, long term immigrant)

Participants also noted the challenge of intergenerational change in New Zealand, where younger people acquired palagi values, while their parents tried to preserve traditional ways; teaching respect towards older people and the community in general as well as preserving other cultural values.

The new generation had some new ideas. They try to think of the palagi ways or the new ways. They watch a lot of TV, they eat food from the outside world ... when the cultures, the different cultures clash, there is confusion. You know that the parents try very hard to bring up their children to look up at the family, to also the community but it is very hard, it is very hard. (Male 40–50 years, established immigrant)

There is no respecting nowadays. That is the first thing our parents teach us – to respect, respect the old people, people older than you, but nowadays... it changed, really changed. (Male 50–60 yrs, long term immigrant)

The challenges faced by early Tokolauan immigrants in the 1960s of living in a cold climate, adjusting to a capitalist society with a

different language, bureaucracy, and the problems of homesickness were ongoing issues for recent immigrants. Changing values towards materialism placed parents under pressure from their offspring in an environment where unemployment and low-income jobs made it difficult for families to cope in New Zealand.

It is like people try to be competitive and that – they saw somebody having that thing, like new boat – 'Oh I can get a new boat.' (Male 40–50 years, established immigrant)

Cause the kids from the Islands they say, 'Can I get this' 'can I get that?' (Male 20–30 years, established immigrant)

Many participants regarded the effects of poverty as a major cause of depression. They identified an association between unemployment, high rent and high food prices and poverty and depression. There was also the cultural pressure of needing to give money to the local community in New Zealand as well as sending money back home to

So if there is any fund-raising, you don't have enough money ... you put the community first and then the family so the problem arises in the family, like, to get the money to look after the kids and stuff, but you have to give the money to the community. That is another problem with the Tokelauan culture. (Female 30–40 years, recent immigrant)

One interviewee described how some Tokelauans have been sent to New Zealand by their family specifically to find a job and send money home. The stress of unemployment, being on a benefit, and failing in this task can lead to illness.

Maybe they were sent from the islands to come here and work and they can't find a job that will pay them enough to be able to send some money. (Female 40–50 years, long term immigrant)

Managing extreme sadness: family, community, faith and the church

Participants identified the primacy of family in providing a safe, loving and respectful environment for people suffering extreme sadness. Tokelauans

looked to fathers of the family for leadership and support, and used the resources of the whole family ('family talk') to help people out of their withdrawal. They were aware of the stress of the unpredictable nature of depression; the risk of suicide combined with their own insecurity of managing the situation was stressful for whole families.

You can't go beyond the family or the parents. If the parents still alive they are the ones supposed to help. (Male 50–60 years, long term immigrant)

That's where you be soft and kind because you know he is sick. You have to give the full love and everybody in the family have to know and treat this like, just like a baby. (Male 50–60 years, long term immigrant)

But the most sad ones is the parents if they do have a son or daughter involved, and they are the ones always sad because they don't know what they are going to face during the day, during the year wherever they go. They are like a prisoner of this person, you know, have to be with them all the time if they think it is really bad. (Male 50–60 years, long term immigrant)

Participants commented that the wider Tokelauan community played an important and different role from that of the immediate family. Whereas family listened and talked, non-family, particularly elders, could give advice and engage depressed people in activities, countering their characteristic withdrawal behaviours.

I don't know what's going to happen but if the old people know that I am sad, they probably sit me down and talk to me. (Male 50–60 years, long term immigrant)

They make you do things so that you don't have time to feel sad or unhappy, like running errands for them and stuff. (Female 20–30 years, long term immigrant)

Other participants talked of the monthly Tokelauan community socials. These are fun events with laughing, joking, dancing, and singing. They talked of trying to keep an ill person occupied by involving them in these social activities.

The whole culture is a very helpful one because normally once or twice a month we gather together, have

fun with our singing and our dancing and our feast. (Female 60+ years, long term immigrant)

Don't let them drift away on their own. ... and if it helps take him or her wherever you go, either to a social or to picnic or shopping. Why not? (Male 40–50 years, established immigrant)

The prominent part faith plays in the Tokelauan community was evident. Eight of the 14 people interviewed talked of the importance of faith and spirituality in the Tokelauan community. The deeply religious nature of the Tokelauan community underlies the importance of spirituality and the church in the therapy of people with symptoms of extreme sadness. One participant described the church as the ultimate help for people with sadness.

I think that (the church) is the biggest help for someone who is really sad. (Female 30–40 years, recent immigrant)

Participants described the healing effects of physical contact – hugging one another at church. One interviewee talked of the positive effect of members of the church community performing Tokelauan Massage and offering prayers for ill people.

They will massage you or do prayers on you. (Female 20–30 years, long term immigrant)

Signs of recovery

Participants indicated that confirmation of recovery is defined by return to normal function. Recovering people have increased involvement in community activities. Their self-care increases and troublemaking diminishes. Isolation ends and new activities are attempted. They speak more and are seen to start life anew. Insightfully however, just as some participants said they had difficulty identifying when someone was becoming sad, at least one person also said that it could be difficult to identify recovery.

Again, we wouldn't have a clue! Unless we have a relationship with that person, we wouldn't know the changes in their mannerisms, and how they

are thinking. (Female 40–50 years, long term immigrant)

Discussion

Although the Tokelauan language recognises only 'extreme sadness', the illness western medicine calls depression is certainly experienced by Tokelauans living in New Zealand. However, this study suggests that doctors may completely miss the presentation of depression in Tokelauan patients. Even if doctors can see past the Tokelauan 'mask of smiling', the diagnosis may be missed by focusing on the classical symptoms of depression (such as disordered sleep, loss of motivation, etc). Instead, listening for symptoms of family and social withdrawal and increasing alcohol use or violence (for males) is vital if this un-named illness is to be diagnosed.

In patient–centred consultations, doctors enter their patients' worlds and explore their illness experiences, 'ideas, expectations, fears and feelings.'¹¹ Two conceptual Pacific models of healthcare provide logical frameworks to use for assessing Tokelauan people in a patient–centred manner. They provide a holistic basis for consultations to help detect and manage social, spiritual or family problems.

The first is the Samoan 'Fonofale'¹² model, in which the house or 'fale' is supported on four pillars ('pou'). The fale roof represents the cultural ideals and beliefs that overarch health care, and the foundation is the family, extended and immediate. Three pillars are a person's physical, mental and spiritual health, and the fourth is other variables such as education, employment, poverty, age and social status. The fale is wrapped in an 'envelope' representative of environment, time and context.

The second is the Tokelauan model of the outrigger canoe, 'Te Vaka Atafaga'. This model incorporates Tokelauan values of community-based living and has six parts, each representing a component of mental well being. The physical body's health is essential for integrity of mind body and spirit and is represented by the canoe's hull. The clear mind and wisdom of the fisherman steering the canoe represents the need

for mental wellness to navigate through life; family are the intertwined fibres of the rope and give strength from cultural beliefs, values and traditions tying the canoe parts to one another; spirituality and beliefs are represented in the sail; the environment around the canoe represents causes of ill-health, including social inequality, unemployment and poverty; and the role of the outrigger is a metaphor for the social supports that keep the canoe upright.

These metaphors of health offer culturally acceptable and holistic ways of managing depression in Tokelauan patients that is also logical and patient-centred. They give permission for doctors to approach depressed patients differently and use various supports appropriately, according to individual need. This research suggests that engaging family, community and church support is likely to be acceptable to Tokelauan patients and integral to their care. Using a general practice team-based approach to coordinating medical care and these other supports may provide these patients with improved care and facilitate wider relationships with the Tokelauan community.

The main limitation of this research was the small number of interviewees. However we continued interviewing until saturation point, when no new information was obtained. The language barrier was also problematic as demonstrated by one interview done entirely through an interpreter. The study's main strength was consulting with the Taupo Tokelauan community and the steering group's guidance.

Our research results may be transferable to other Pacific people. It is likely they have similar issues with diagnosis and treatment of extreme sadness. The Te Vaka Atafaga approach is a Tokelauan model but other Pacific people have accepted the Samoan Fonofale model, 14 which is very similar. Using these models as a holistic treatment approach involving family and spirituality will possibly be successful for doctors treating Pacific people with extreme sadness. The results of this study can be applied to other cultures where communication of culturally coded signs of sadness causes diagnostic and therapeutic challenges. Further research needs to be conducted to confirm this.

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