

QUALITATIVE STUDY OF
ELDERLY PACIFIC INFORMAL CAREGIVERS
OF A YOUNG PERSON WITH AN ILLNESS
OR DISABILITY

CLINICAL RESEARCH UNIT
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The National Health Committee can be contacted by phone on 04 496 2071 or by postal mail at PO Box 5013, Wellington, New Zealand.

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The National Health Committee would like to thank all those who contributed to this document for their willingness to share their ideas.

First published in July 2009 for the National Health Committee, New Zealand

ISBN (document): 978-0-478-31951-4

ISBN (web): 978-0-478-31952-1

HP: 4816

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So he needs someone with love and patience, love and patience. Love is there right from day one when we found out.

(Niuean grandparents talking about their grandson diagnosed with a neural tube defect)

... I believe that as grandparents – scary when my grandson is sick: His breathing gets worse – and I give him his inhaler – count one to six – see his ribs stretch, then ring his mother at work. Other medicine from doctor does not work. I am asthmatic too. I get scared as a grandparent – I don't want him to die.

(Cook Islands Māori grandmother during Cook Islands Māori focus group)

There are times when we are both sick and I have to be really strong and have the courage to look after him as I know that he is incapable of looking after himself.

(Tongan grandmother)

It was when she was about one year old when my granddaughter started suffering from epilepsy. When she was diagnosed with epilepsy it was difficult for us to handle. This illness really scares you because when she has seizures you just don't know what to do, just putting her in cold water then we go to the hospital.

(Samoan grandmother during Samoan focus group)

... the day we found out that our grandson had cerebral palsy it was like a funeral.

(Niuean grandmother speaking about her grandson)

Foreword

This landmark study highlights the unique challenges facing elderly Pacific caregivers in New Zealand, especially where an older person is caring for a young person with a disability or illness.

Dr Siale Foliaki, the research team at Vaka Tautua and the National Health Committee are to be congratulated for highlighting one of the more difficult care-giving challenges in New Zealand.

The study confirms the observations and experiences of many caregivers in the community. It provides a rich picture of the range of issues facing this segment of the Pacific population and presents a number of challenges for government in terms of providing appropriate services and assistance for caregivers.

In many respects, the situations described in the report affirm the caring roles of older persons in traditional Pacific cultures and how they work well. However, socioeconomic circumstances, deficiencies in knowledge, and rigid and inflexible care systems in New Zealand have created a unique situation where, in some instances, the risks of a care-giving arrangement outweigh the benefits. In this situation alternative options should be explored immediately.

Elderly Pacific persons who care for others often have health problems of their own, and are expected to do their best in less than ideal home environments, and with limited facilities and support. These kinds of arrangements are often unavoidable due to the family's economic circumstances and cultural expectations and practices. This situation is unacceptable and more needs to be done.

Solutions must encompass more than just the health sector, given the socio-economic issues raised by the report. For example, provision of adequate housing would

significantly help alleviate the physical and psychological problems faced by elderly Pacific caregivers.

The vulnerability of elderly Pacific caregivers must be acknowledged at a policy level. Their needs should also be addressed through stronger and more effective inter-sectorial collaboration.

Society is quick to judge when things go wrong, so effective solutions are required before problems occur for caregivers and young people in their care. We need to do better.

Dr Colin Tukuitonga
Chief Executive
Ministry of Pacific Island Affairs
August 2009

From the principal investigator

Kia ora, ni sa bula vinaka, fakaalofa lahi atu, kia orana, talofa lava, malo e lelei, taloha ni, halo olaketa, ia orana, kam na mauri and warm Pacific greetings.

On behalf of the Pacific community I commend the National Health Committee for seeking to understand the complex needs of elderly Pacific peoples who have been thrust into a role of providing care for young people or children with a chronic illness and/or disability.

As principal investigator I believed that I understood the many challenges our elderly Pacific caregivers faced in caring for these special members of their families. This assumption proved very wide of the mark. Part way through the individual interviews that were conducted as part of the exploratory qualitative research method it became apparent to me that I had seriously underestimated the challenges the elderly Pacific caregivers had to confront on a daily basis. As a result I became acutely aware that to do justice to the sacrifices these caregivers were making, we as a research team had a responsibility to get the research right. To document the true nature of the challenges they faced we needed robust information backed by good research methodology.

The results of this research project go some way to addressing the major gaps in our understanding of this important area. It is just a start, however, and I look forward to further research in this area and the development of policies and services that respond to the needs of this special group of people.

Dr Siale 'Alokihakau Foliaki (MBChB FRANZCP)

Principal Investigator

About the team

Dr Siale ‘Alokihakau Foliaki (MBCChB, FRANZCP) is the Chairperson of Vaka Tautua Board of Directors and principal investigator for this project. He is a consultant psychiatrist at Counties Manukau District Health Board.

Dr Vili Nosa (PhD) is a lecturer at the Department for Pacific Health, School of Population Health, University of Auckland. He is a highly regarded Pacific academic who is an expert in qualitative research in the Pacific context.

Mrs Sandy Birkenhead (RGN, BA), project manager, has a background in health, nursing, education and social services management. Sandy has held numerous managerial roles in the public and private sectors. She also has personal experience as caregiver of a family member with a disability and therefore brought a special empathy to the participants and interest in the research topic.

Mr Haniteli Kanongata’a is an independent Pacific cultural consultant who assisted with expert review of the Tongan translations and was a source of cultural knowledge for the report.

Mr Tunumafono Avaula Fa’amoe is an independent Pacific cultural consultant of Samoan heritage who assisted with expert review of the Samoan translations and was a source of cultural knowledge for the report.

A word of gratitude

The true measure of any society is how well it cares for the most vulnerable of its members. The old and the young, the sick and the disabled are the most vulnerable. Elderly Pacific peoples caring for disabled or chronically ill children or young people bring two of the most vulnerable groups in society together, and the findings of this project highlight the challenges that arise. It was a privilege to undertake this research but unless there is action to improve the plight of these elderly Pacific caregivers then the effort will have been wasted.

Improving the lives of elderly Pacific caregivers can only occur if the challenges they face are accurately recorded. A burden of responsibility was given to Vaka Tautua to carry out this research: its successful completion is an important part of the process of getting the right help to the people who most need it. It is therefore important to acknowledge the efforts of many people who contributed to the successful completion of the task that was set. The research team would like to express our sincere gratitude to everyone who made this report a reality.

Firstly, to our Pacific elderly caregivers who gave their time and shared their experiences willingly. Research of this nature would not be possible without people volunteering to participate, therefore on behalf of Vaka Tautua and the research team a very sincere 'thank you'. A special thanks to the staff of Vaka Tautua, particularly the Chief Executive Officer Philip Beilby and his operational manager Manu Fotu for overseeing the staff and systems that made the project run smoothly. Thank you also to Kathleen Tuai-Ta'ufo'ou, Gaylene Harvey, Tina Matiti and Temasi Elisaia, Telesia Tanoai and Augustine Carpentier for organising the focus groups and taking such good care of our elderly caregivers who attended. Special thanks to the facilitators Tunumafono Ava'ula Fa'amoe, Lolo Filiiai, Angeline Hekau, Fale Puka and our translators Tonga Enosi and Shirley Fa'amoe and, lastly, the elderly group community co-ordinators Pepe Tuake, Mary Tuake, Loimata Lafele and Reverend Roy Smith.

Dr Siale 'Alokihakau Foliaki (MBChB FRANZCP)

Principal Investigator

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Executive summary

The results of this qualitative study indicate that elderly Pacific caregivers are an extremely vulnerable group of people for many inter-related reasons. The level of vulnerability they experience poses risks both for the caregivers and for the vulnerable children they look after, and creates a moral imperative for urgent action. The problems are not insurmountable but require a co-ordinated response from both Crown agencies and the Pacific community. The major findings follow.

- Elderly Pacific caregivers demonstrate a high degree of resiliency, which is grounded in their spirituality and Christian faith, in the face of many difficult and challenging circumstances.
- Poverty is the single most difficult issue faced by elderly Pacific caregivers. Pacific peoples aged 65 and over have the lowest median income of any group in New Zealand. Yet elderly Pacific caregivers face significant additional costs as a result of caring for children or young people with a chronic illness or disability.
- Poor quality housing is a direct result of poverty. Unstable housing arrangements make a vulnerable segment of the population even more vulnerable as important relationships and networks are lost if they and the children they care for are forced to move. Elderly caregivers who live in homes provided by Housing New Zealand Corporation (HNZC) are often in a better situation than those who rent privately.
- Elderly Pacific caregivers experience significant health problems both physical and psychological. The conundrum they face is that resource limitations and cultural factors ensure that the health and wellbeing of the children takes precedence. In most cases the health of elderly Pacific caregivers involved in the study was being negatively compromised by taking on the role of providing care for sick or disabled children or young people.
- Elderly Pacific caregivers experience a high level of social isolation as a result of having to remain available to the child or young person in their care. Social isolation is a significant risk factor to both psychological and physical wellbeing. Traditionally held beliefs about illness causation in the wider Pacific community

- The children and young people in the custody of elderly Pacific caregivers have complex medical problems. Important information, knowledge and understanding of the medical conditions by most of the elderly caregivers is very poor, jeopardising the long-term health outcomes for the children in their care.
- Elderly Pacific caregivers demonstrate a high level of confusion as to the specific roles of individual health and social service professionals and agencies.
- Elderly Pacific caregivers demonstrate access problems to health and social services and appear not to be aware of entitlements they may be eligible for.
- Elderly Pacific caregivers' access to important health information is poor and they often adopt a literal approach to actioning whatever information they are given.
- Elderly Pacific caregivers experience a heightened degree of fear and anxiety as a result of lack of understanding, knowledge and professional support surrounding the complex medical problems experienced by the children and young people they are responsible for.
- Elderly Pacific caregivers have strong traditional beliefs that affect health choices which may impact on the care given to children or young people they are responsible for.

1.0 Introduction – background

1.1 Research project rationale

In 1998, the National Health Committee (NHC) released *How should we care for the carers?*, a consultation document which highlighted the significant contribution made by unpaid carers and family members who care for someone with an illness or disability. Since that time there has been increasing recognition that informal caregiving often goes unrecognised and unsupported by government health, disability and social services. This has culminated in the development of *The New Zealand Carers' Strategy and Five-year Action Plan* that was launched by the Ministry of Social Development and the Carers' Alliance in April 2008.

The NHC has undertaken to provide advice to the Minister of Health on the significance and impacts of the informal caregiving role for the lives, health and wellbeing of informal caregivers, and to identify pathways for mitigating negative impacts. The NHC is particularly interested in finding out more about New Zealand's informal carers, about whom little research has been done and who are less 'visible' for various reasons. Many diverse groups of informal carers fit this category, but the NHC chose to focus on one particular group for the purpose of this research: informal elderly Pacific caregivers of young persons with an illness or disability.

A major reason behind this decision was the limited research into Pacific peoples' experiences of informal caregiving and the complexity involved in understanding this group due to the many nations, languages and cultures represented amongst Pacific peoples living in New Zealand. In 2006, there were 22 distinct Pacific populations; the four largest being Samoan (49 percent), Cook Islands Māori (22 percent), Tongan (19 percent) and Niuean (8 percent) (Statistics New Zealand 2006). Managing this ethnic diversity has been addressed by careful study design considerations captured in the methodology section.

1.2 Demography of Pacific peoples in New Zealand

At the time of the 1991 census there were 167,706 Pacific peoples in New Zealand. In the 1996 census the Pacific population had increased to 202,233 people making up 5 percent of the total 3,373,926 people resident in New Zealand. By the time of the 2001 census, the total population had increased to 3,737,277 and the proportion of New Zealand residents who identified as Pacific had increased to 6.5 percent. In the last census in 2006 there were 265,974 people who identified as Pacific (a 59 percent increase from the 1991 census). Significant future growth is projected, with 15 percent of all babies in New Zealand born to Pacific parents (Statistics New Zealand 2006).

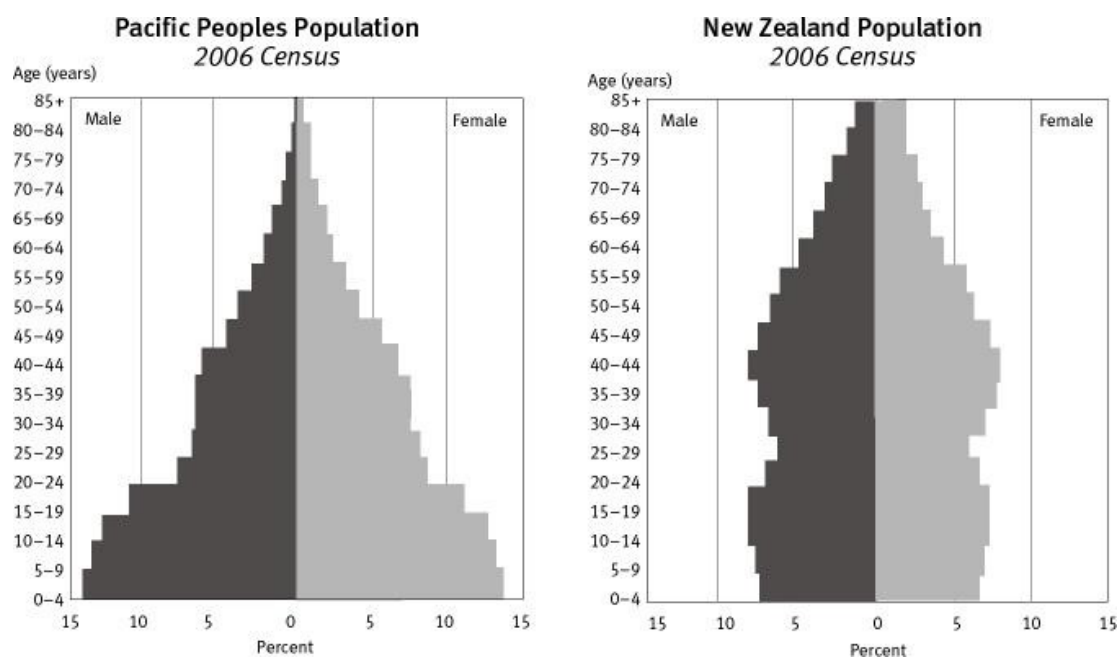
Thirty-eight percent of Pacific peoples (100,344) were aged less than 15 years in 2006, down slightly from 39 percent in 2001. This was much higher than for the New Zealand population overall (22 percent).

Relevant to this research project is that the number of Pacific peoples aged 65 years and over has been increasing.

- In 1996 there were 5,871 Pacific elderly.
- In 2001 there were 7,632 Pacific elderly.
- In 2006 there were 10,083 Pacific elderly.

In 2006, those aged 65 and over made up 4 percent of Pacific peoples, up from 3 percent in 1996. This is much lower than for the overall New Zealand population, of whom 12 percent were aged 65 years and over in 2006 (Statistics New Zealand 2006).

The following population pyramids highlight the significant differences between the New Zealand Pacific peoples and the total New Zealand population, particularly the marked differences in the two populations through the life cycle leading towards old age (Statistics New Zealand 2006).



There is no census information readily available regarding how many Pacific elderly are providing informal care to children or young people under the age of 18 years who have a chronic illness or disability. What is known is that grandparents who are assuming full responsibility for raising their grandchildren are an increasing phenomenon in New Zealand. The 2001 New Zealand Census recorded that over 4,000 children were being parented by their grandparents, although the ethnic breakdown was not available (Statistics New Zealand 2002).

1.3 Disabled or chronically ill Pacific children

Twenty percent of the New Zealand population reported living with a disability in 2001, showing no change since the 1996-1997 disability survey. The rate of disability for Pacific peoples was reported as one in seven. An estimated 28,100 (14 percent) of Pacific peoples (adults and children) reported having a disability in 2001. Almost all Pacific peoples with a disability (98 percent) were living in private households in the community. Of this group, 5,700 (21 percent) were children under the age of 18 years (Statistics New Zealand 2001). There are no summary figures available regarding the number of Pacific children with significant chronic illness, but the evidence presented below indicates that Pacific children experience significant rates of childhood diseases that have the potential to cause long-term chronic illness.

Rheumatic fever is potentially life-threatening and leads to long-term cardiac complications that have a major impact on a child's health. Rates of hospital admission for Pacific children (0-24 years) were 41 percent higher (31-55 percent: 95 percent CI) compared with European children during the 2002-2006 period, with those Pacific children going on to develop rheumatic heart disease 27 percent higher (18-39 percent: 98 percent CI) (Ministry of Health 2003).

Bronchiectasis is a devastating respiratory condition that if poorly treated leads to chronic breathing problems, respiratory failure and early death. By their fifteenth birthday 1:1700 New Zealand children will be diagnosed with bronchiectasis, with the incidence in Pacific children 12 times higher than that for the general population (Twiss et al 2005).

Asthma is another respiratory condition that when moderate or severe can significantly affect the quality of life for young people. Although mortality has decreased, Pacific children have the highest rates of hospital admission and morbidity (severity) for this disease (Pattemore et al 2004). Whatever the illness or disease, Pacific children appear in most cases to have higher rates of prevalence for the conditions that lead to chronic illness (Ministry of Health 2008).

The statistics present clear evidence for a disproportionately large number of Pacific children with significant disabling illnesses and/or disabilities that require the support of informal caregivers. The exact number of Pacific elderly who provide this care is not known but there is sufficient anecdotal evidence to suggest that there are large numbers (and growing) either solely looking after, or contributing significant amounts of time and energy in the service of, these children or young people.

2.0 Research design outline

The NHC's purpose in commissioning the research was to find out about selected older Pacific informal caregivers' experiences of caregiving, and what they consider they need to support their own health and wellbeing and to support them in their caregiving role.

The NHC stipulated that areas of inquiry must include:

- experiences of caring for a young person with an illness or disability
- perceptions held by older Pacific people of their roles as caregivers in New Zealand
- key issues experienced by older Pacific people that support or compromise their ability to provide adequate care
- factors that compromise and/or improve and enhance the health and wellbeing of older Pacific informal caregivers
- approaches for promoting positive roles of caregiving and wellbeing for older Pacific informal caregivers.

(Ministry of Health Request for Proposal 2008)

The study was designed to illuminate these areas of inquiry. A full discussion of the research methodology can be found in the appendices, but essentially this research project had an explorative qualitative research study design. A total of 24 informal elderly Pacific caregivers participated. Participants were separated into focus group and individual interviews. Two focus groups were held with the Samoan and Cook Islands Māori communities as these are the two largest Pacific groups in New Zealand. Eight individual interviews were conducted with four Tongan, two Niuean, one Tokelauan and one part-Tahitian, part-Tongan participant.

Participants had a choice of interviews being conducted in English or their first language, with all non-English interviews transcribed verbatim into the first language and then translated into English. Grounded theory was used to guide the inductive process of coding incidents in the data and identifying analytical categories as they emerged from the

data. The categories were then collated into major themes and subthemes and are presented in section 4, followed by a critique in section 5.

2.1 Participant demographics

There were 24 participants but in the final analysis only 20 who met the criteria for inclusion had their data analysed: six Cook Islands Māori, six Samoan, four Tongan, two Niuean, one Tokelauan and one Tahitian/Tongan. They were all born in the Pacific and their ages ranged from 59 to 77 years, with the majority being in their late 60s; 16 participants were female and four were male. The age of the children they cared for ranged from 12 months to 18 years of age. All the elderly caregivers were grandparents to the children and all had other grandchildren. The range of illnesses and disabilities included: bronchitis, asthma, eczema, autism, intellectual disabilities, epilepsy, cerebral palsy, Cri-du-chat syndrome, Down syndrome, syringomyelia and ADHD (Attention Deficit Hyperactivity Disorder).

The completed analysis contained 26 categories which have been grouped into nine thematic areas, as many of the categories fitted together under the themes identified.

3.0 Cultural considerations

For if you want sight and insight into my psyche, you will have to speak to the gods who inhabit it. You have to eavesdrop on the dialogue between my ancestors and my soul. You have to address my sense of belonging. I am not an individual; I am an integral part of the cosmos. I share divinity with my ancestors, the land, the seas and the skies. I am not an individual, because I share a "tofi" (an inheritance) with my family, my village and my nation. I belong to my family and my family belongs to me. I belong to my village and my village belongs to me. I belong to my nation and my nation belongs to me. This is the essence of my sense of belonging. These are the reference points that define who I am, and they are the reference points of other Samoans.

Tui Atua Tupua Tamasese 2003

Undertaking qualitative research amongst Polynesian people using non-Polynesian epistemologies, paradigms or frameworks would be methodologically unjustifiable. The oratory of distinguished Samoan Tui Atua Tupua Tamasese clearly articulates the essence of being Polynesian. The study design is constructed around the centrality of this collective view of the world.

The extensive literature on collectivism (versus individualism) describes these concepts as different systems of ideas, images, and understandings about people, groups and society. (Sinha and Verma, 1987; Triandis 1990a, 1990b; Hui and Triandis, 1986; Georgas 1989; Markus and Kitayama 1991a). Exposure to Western societies influences the degree of collective versus individual thought. Although different Pacific communities have differing degrees of exposure to Western society, it would be safe to assume that collective views persist strongly in the age group under consideration.

Collectivism focuses attention on maintenance of social norms and performance of social duties as defined by the group (Sinha and Verma 1987; Triandis 1990a, 1990b). Within

this world view, development and maintenance of a set of common beliefs, attitudes, and practices is extolled and the importance of co-operation of group members is highlighted (Hui and Triandis 1986; Georgas 1989; Markus and Kitayama 1991a). The group is seen as the basic unit of survival (Hui and Villareal 1989) so that attempts to distinguish between the personal and the communal are likely to appear false and be suspect (Triandis 1990a, 1990b).

Social responsiveness is valued, and individuals are expected to attain understanding of their place within the group by reflecting on and attending to the needs of the group (Cousins 1989; Markus, and Kitayama 1991a). Finding worth in their individual selves comes through their active contribution and belonging to the group. It is within this framework and through this lens that each of the study requirements, particularly the analysis, was undertaken.

4.0 Key findings

4.1 Theme one: Resiliency

As we warmly embraced each other, my older sister cries out, 'Night and day, I have been sitting here and watching you, and your mum came, and you're ending your life with her' ... it was a very heart wrenching moment... as she was taking her last breaths....

Elderly Tongan grandmother

The grandmother quoted above drove straight from the airport to the hospital where she gave thanks to God for allowing her to be present at the death of her daughter. That same moment she became the permanent caregiver to her 29-week-old grandson who was born with Down syndrome, marked intellectual impairment and epilepsy.

The findings from the project describe a range of difficult circumstances and challenges that elderly Pacific caregivers face as a direct result of taking on the responsibility of caring for chronically ill or disabled children. A major theme to emerge from the study is the ability of these caregivers to cope when they could easily be overwhelmed. Their resiliency stood out strongly.

I don't have time to feel sorry for myself and so there are others that are needing love and support more than myself. And so by doing that you don't actually realise that by helping other persons who are really in need you are also helping yourself so its really doing things for others that you are doing things for yourself. And that's how you give yourself the strength and knowledge and understanding to be able to help yourself because you are helping others. That is really powerful and when you help others you come out a better person. You are giving your time, you are giving love, your service and serving others first, when you put others first you are the one actually benefiting. It may sound funny but it works for me.

Tokelauan grandmother

Individuals can expect to experience periods of change, disruption and even crisis throughout the life span. Older adults experience significant challenges as they negotiate the last phase of life, including bereavement, loss of socially valued roles and chronic and accumulating health problems. As will be demonstrated by the research data elderly Pacific caregivers face the challenges of the ageing process but many more besides. With these many challenges in mind it was evident to the research team that, almost without exception, the elderly Pacific caregivers in the study were bearing up to the very difficult and stressful day-to-day problems and at times frightening medical emergencies that arose in the care of their chronically ill or disabled young people. Their sense of duty was very strong.

... my Heavenly Father what I have done must be my duty. I just have to go with him, go straight, and the love for my grandchildren I hope that they will grow up and understand the position... where we are now, so [they] can have ahead a good life for their future....but for me now, I'll be happy, I have to...

Tongan grandfather

There were times when the commitment to their children and young people had an impact on their physical wellbeing:

...Over all our children, we have never come across sickness like this. At the age of 65 I have to do something with my high blood pressure and diabetes and how can I see to this sickness in this child. I have to look after myself too. I just drop down when this sickness comes up.

Cook Islands Māori grandmother

And on their psychological wellbeing:

There is a lot of things that add up to that depression. It's struggling with the children to meet their needs and financially and sometimes [I am] very tired in sorting them out with their differences like they are children, we must understand that they are children, that is the only thing that overcomes my stress and depression is to understand the condition that I have. And think

not to be depressed and ruin my health but try and sort it out and be calm and understand. Understanding is the main thing.

Tahitian/Tongan grandfather

This elderly caregiver was forced back into an ongoing sole-caring role at age 63 following the severe mental illness of the children's mother. There were three children in his care aged 14, nine and seven years, with the nine-year-old having moderately severe behavioural problems secondary to his intellectual disability. The grandfather also cared for the children's mother.

The data gathered from the research process will demonstrate the hardship that almost all of the elderly Pacific caregivers experienced. The willingness with which they were prepared to look after the children and young people in their care despite these conditions was clearly evident and aptly demonstrates their resiliency.

4.2 Theme two: Poverty

Praise be to God for he is a loving God, sometimes we have no food, I pray to God and someone will turn up asking how we and my grandson are... if we have nothing then I just put the crackers on the table.

Tongan grandmother

Pacific peoples are disproportionately represented in lower socioeconomic brackets. Compared to 8 percent of the total population, 27 percent of Pacific peoples meet the criteria for living in severe hardship; an additional 15 percent live in significant hardship, and only 1 percent report 'very good living standards'. Home ownership rates are also much lower in the Pacific community, and Pacific peoples are more likely to experience overcrowding in their homes (Ministry of Health website 2009).

4.2.1 A vulnerable group

Elderly Pacific caregivers are among the poorest and most vulnerable groups of people in New Zealand society. The median gross annual income of Pacific peoples aged 65 and over at the time of the 2001 Census was \$9,900. This compares with Māori elderly who had a median gross annual income of \$11,700 and European New Zealanders of \$13,100 (Statistics New Zealand 2004). In addition the study uncovered an interesting phenomenon that affected elderly migrants from the non-New Zealand Pacific territories of Niue and the Cook Islands. These elderly migrants enter New Zealand under the reunification policy of the Immigration Act but are not eligible for a pension until they complete a 10-year stand-down period. The number of elderly Pacific peoples in this category may be small but adds considerably to the financial hardship being experienced by their households.

An elderly person's level of net worth is influenced by educational qualification (a higher qualification is associated with a higher net worth), number of children (the presence of children is associated with lower net worth), and inheritance (receipt of an inheritance is associated with higher net worth) (Statistics New Zealand 2004). Elderly Pacific peoples are more likely to have: poorer educational qualifications; more children; not received an inheritance; and lower levels of home ownership.

The monies all come from the benefit and budget services helps us controlling our finance; making sure all the bills are paid and they gave us whatever is left. That's how we survive now, pay the bills the left over sometimes \$50 over a week, you know whatever left we use it for shopping, sometimes we got \$50 over a couple of weeks.

Tongan grandfather

The gentleman quoted here spent the remaining money he refers to predominantly on groceries and was the caregiver for three children aged 14, 12 and 11. The 11-year-old suffered from a diagnosed conduct disorder. The family had recently been forced to move to a different suburb (due to sale of their rented house). The grandfather wanted to keep

the children in the same schools but this posed problems with transport costs. He often would take the children to school in the morning and then sit in his car and wait until the end of the school day because he could not afford the petrol to make the trip home and back again in the afternoon.

I just take in the morning and I wait there until 3.00pm, just pick them up and we come home...I try to tell my case manager at WINZ and no help at all, that the same thing I got sometime we running the van ... waiting for the next money to come, you know to get the gas in ... very very hard for me.

Tongan grandfather

Some participants with well-paid jobs had to leave these to care for their disabled or ill grandchildren, even though they knew this would cause severe financial hardship.

Grandfather– She (grandmother) is also a retired teacher and that was part of her, and she was teaching at the time and when the pressure came... umm.

Grandmother – That’s when I gave up teaching.

Facilitator – You gave up teaching to look after your grandson?

Grandmother – Yes.

Facilitator – But that would have impacted on your income, if you were teaching you would have been getting paid for that?

Grandmother – Yes.

Facilitator – How did you cope financially?

Grandfather – We didn’t. We didn’t cope. At the time I was the only breadwinner and we struggled. Those were the challenges that we confronted and uh my grandson’s parents helped out financially but ah we still struggled.

Grandmother – At that time I didn’t receive any income at all. I wasn’t thinking of the money, I was thinking of my grandchild.

Elderly Niuean grandparents

4.2.2 Additional costs of caregiving

The results of the study indicate two major reasons for elderly Pacific peoples becoming caregivers for chronically ill or disabled children or young people.

1. Economic necessity.
2. Care and protection issues.

The economic necessity is simple. The parent(s) of the child must re-enter the workforce to generate income to meet the financial obligations of the household. The elderly caregiver takes on the role of pseudo-parent and this often extends to out-of-work time as well, as younger parents participate in after-work activities.

Care and protection issues are much more complex and fall into the following categories.

- The parents were not in the country.
- The parent was impaired – mainly health-related problems (two of the grandparents had children suffering from schizophrenia and were forced to take on the care of the grandchildren as a result).
- The child was placed in their care by social welfare agencies.
- The child's parent had died and the other parent had absconded.

Whatever the reason behind elderly Pacific peoples becoming caregivers there are always additional costs associated with this task. Elderly caregivers are required to meet the increased cost of shopping, electricity, transport, petrol, doctors visits and medications to name but a few. The additional costs of living with a family member with a disabling condition has been partially recognised by governments but largely remain the responsibility of the individual (Fawcett 1996). Aspects like meeting dietary needs, buying special soaps, or providing suitable transport can be hidden costs.

Thank you I will share what I am going through with my granddaughter. The issue we face in our family is around finance due to her having specific soaps that she uses to bathe in, we have to buy

the specialised soap just for her not only that but as I mentioned earlier that her medication is expensive. Within any parent there is always a feeling of anguish because within my family it's only myself, my husband has passed away.

Cook Islands Māori grandmother

This applies to medications which are often required in large amounts. The caregiver quoted below is reporting on the costs of eczema creams that are required in large amounts as the skin condition affects large proportions of their grandchild's body.

We would take him to the doctors and they give us [eczema] cream, and finding the creams expensive too.

Samoan grandmother

Another example given in the data indicates the difficulties that caregivers face when dealing with the demands of the children or young people in their care.

My granddaughter wants expensive stuff and what we have found, that if we do not do what she wants she would walk and there have been many times where we have gone out to search for her, so a strategy we have is to keep her happy and that is by doing what she wants even though its expensive but we do this to keep her happy. Doctors have told us if we keep her happy then there will be an improvement then there will be an improvement with her mentally and our whole family understand and are clear with this issue we have.

Samoan grandmother

This example highlights another thread that ran through the data. Many of the elderly caregivers applied very literally the advice that doctors gave them. For example, some of the participants with children with asthma told their children never to run and always walk slowly as the doctor had told them not to let the children get exhausted.

None of the participants in the study were financially well off. The majority were very poor. One participant had some savings before inheriting the care of her grandchild on the death of her daughter. She used her small retirement savings caring for her grandson.

I end up withdrawing all my money every day to pay for all our expenses and my grandson, bank probably think that I am an idiot for such actions but it was important for me to get new clothes for my grandson and also school clothes.

Tongan grandmother

Of concern are the ongoing cultural demands that elderly Pacific caregivers still contend with. These additional financial burdens add to the poverty experienced by elderly Pacific caregivers.

... and she was in tears, and she said to me 'I have given all my money but it's not enough, but I want WINZ to give me some more' and I said 'Mama WINZ does not work that way'. I said 'WINZ is not giving you the money for the church. WINZ is giving you money for your care, and this is how you use your money for your care, you are still living here with your son and daughter but this money is for you and WINZ know exactly how much you need and how you are going to spend it. WINZ is not giving it to you so you can give it all to funerals or weddings or twenty-first birthdays or things like that, otherwise you are left with nothing.

Tokelauan grandmother

4.2.3 Housing

Almost all the participants had specific requirements for housing as a result of caring for a child or young person with a chronic illness or disability.

I thank God as my children have got a new place to stay because my grandchild was taken to Starship and although there has been many times request were put in with 'Housing' regarding a bigger place, even the doctor supported that a proper place be found for the children to live in, and I thank God for they now have a house which has four bedrooms and everything is good in my observations.

Samoan grandmother

The above quote is an example of what happens when HNZC matches the needs of people with appropriate housing. Prior to this house being made available to the elderly caregiver this year, she had been living with her daughter and five children in a small two-bedroom flat for the last seven years. The long-term overcrowding was believed to have contributed to hospital admission of one child; this precipitated specialists placing high level pressure on HNZC. An elderly caregiver who was renting privately had a different experience:

Grandfather – The cockroaches, the hot and the cold water doesn't connect, the kids they [are] using the bucket.

Facilitator – They use the bucket to wash themselves?

Grandfather – Yes ... they got the shower, but there is no hot water ... I don't know what the system here ... I just found out cockroaches and what you call the hot water doesn't work together [with] the stove since we moved here from day one you know ... they haven't fixed the stove.

It was difficult sitting in the home of this elderly Tongan gentleman, who cares for three children under the age of 14, and seeing first-hand the conditions described. The home was clean and filled with photographs of family but there was no escaping the obvious: the damp cold air coming through the broken window, the peeling wallpaper, the mould and mildew on the ceilings and skirtings. The full force of this harsh reality begs the question: are these the living standards our society thinks are acceptable for New Zealand children?

According to this gentleman he has been on a waiting list for a HNZN home for some time. The house clearly did not meet legal requirements, but until HNZN offers him an alternative, this privately rented house is the best he can get.

Apart from the legal and health imperatives, improving access to appropriate housing, and housing modifications, are important considerations for caregivers of children and young people with a significant disability.

... the problem we have at the moment with housing is that the house was built when the child was nine years old, he is now 18 years old. He has a lot of equipment that he uses in the home, eg, wheelchair, standing frame, walking frame so with these frames and facilities that he is using he is at the stage where he almost can't fit through the doors due to his equipment getting bigger.

Samoan focus group participant

4.3 Theme three: Health of caregivers

All participants in the study had physical health problems of varying degrees consistent with their advanced age. In some cases they had multiple health problems that affected their ability to provide adequate care; these problems were exacerbated by the care being provided.

There are times when we are both sick and I have to be really strong and have the courage to look after him as I know that he is incapable of looking after himself.

Tongan grandmother

Despite the multiple and, at times, very serious medical problems, the caregivers as a general rule paid scant regard to their own health and wellbeing. They focused a high degree of effort and energy on attempting to ensure the best quality of life they could for their charges. The grandmother quoted above cares for a very large young man (over twice her size and two-and-a-half times her weight). Her greatest fear is that he will have a seizure while on the toilet as there is no way she could help him into a position to ensure

he had a clear airway. She lives with her elderly sister and if the young man in question has a grand-mal seizure they ring nearby relatives for help.

An elderly caregiver talking about his wife says:

... she has conditions of her own as well but she has switched herself off and switched her grandson on. Whatever is wrong with her is like she doesn't want to know what is wrong with her she would rather look after her grandson.

Niuean grandfather

Many of the caregivers had high blood pressure and diabetes.

At the age of 65 I have to do something with my high blood pressure and my diabetes and how can I see to the sickness in this child. I have to look after myself too. I just drop when the sickness comes up. If nothing comes up I feel good.

Cook Islands Māori grandmother.

A common problem was the high energy of the children and the understandably low energy levels of the caregivers.

For me looking after a four-year-old autistic child is a real challenge. Autistic child[ren] are very very active and can only sit still a little while and then off again.

Cook Islands Māori grandmother

The significant issue is that the caregivers have the desire and psychological willingness to look after the children but their advancing years mean their physical capacity does not match the level of care required.

Facilitator – *Where do you get your energy from to carry out your responsibilities?*

Grandfather – *Sometimes I get energy from eating, but I just want to do it; sometimes my body is tired and weak but that does not mean that I will give up, my heart is strong.*

Tongan grandfather

There are health and safety issues for this elderly caregiver as his property backs onto the railway tracks that run through South Auckland and his grandchild is small enough to climb through the wire fence in their back yard. The road-side has no fencing and he has had to pull his granddaughter with Down syndrome off the road on many occasions.

4.3.1 Social isolation

There were varying degrees of social isolation amongst the study participants. A few were completely looking after the children in isolation from family, church participation and wider community activity, but this was the exception, with the majority having regular contact with family and participating in church and community activities.

Facilitator – *Do you ever feel isolated or lonely because you live alone...because in Tonga you have plenty of friends and neighbours and when you wake up you have people to talk to, but here, it's different and you have language difficulties.*

Grandfather – *[I] have been thinking about that a lot, no one to talk to...waking up to my granddaughter... TV does not give me peace ...*

Facilitator – *Like how we have been talking this morning?*

Grandfather – *I feel warm now ...*

Tongan grandfather

Without exception, the participants were grateful for the opportunity to discuss the issues surrounding the care of their grandchildren and many expressed how much

better they felt at the conclusion of the interview; this demonstrates their usual lack of opportunity to talk through their thoughts and feelings. This is possibly due to isolation, and perhaps to no one taking an interest in how they were feeling and coping with the demands placed on them.

4.3.2 Parenting

A strong theme to emerge from the study was that caregivers found it a daunting task to have to re-learn the art of parenting children and young people who faced the additional problems of illness or disabling conditions. This theme has synergy with the topic of social isolation because, as mentioned above, the more overwhelmed the caregivers felt the less able they were to care for the children and young people they were responsible for. They were struggling with the notion of having lost something fundamental in their transition from home in the islands to living and caring for children and young people in New Zealand.

Yes we've lost the Tokelau upbringing. We've lost the values of the culture what families... like the culture there is mostly families because so you know your place in your family. You were taught to be polite to the elderly people, you were taught to know your position in the family as a girl, as a boy, how to respect one another. You were taught how to talk, who you were talking to... respectfully. You were taught how to even walk.

Tokelauan grandmother

The strong commitment to the care of the children is highlighted by comments caregivers made about the diminishing quality of care they see, at times, amongst some of their own families and the wider community.

My belief, which is different from the rest, is the reason why the children are on the streets is because they do not have boundaries and are not being cared for properly because the parents have gone to do their own thing leaving the children to do their own thing and I believe that if both the mother and the father are one in caring for their children that would mean a good future for the children.

Samoan grandmother

There were significant differences between the individual participants in the level of control they believed they had over their circumstances. The less in control they felt the more basic was the care they delivered to the children. In some situations the care was of a very basic level. They cooked the meals and cleaned the house and made sure the children were ready for school and managed to get them there and back. The other activities of parenting: the school work, the social outings, and wider activities like music, sport or artistic pursuits and ultimately the teaching of who they are and their sense of identity as reflected in the quote above, were missing. This notion of ‘not doing the best’ by the children filtered through the data and this anxiety was related to engaging with complex medical, education and support agencies which, due to language and cultural barriers, they felt unprepared for.

4.4 Theme four: Health knowledge

Providing quality care to disabled or chronically ill children or young people requires an appreciation of their ongoing health needs and possible complications that can result from their condition. The more complex the illness or disability the more complicated the knowledge that is required to provide quality care.

Facilitator – *Do you know what Down syndrome is?*

Grandfather – *I know nothing about that, but the way I observe her, I don't know the Tongan word for that, for if she's here, she has her own way of playing, rather funny and that's the only thing I noticed about the little girl.*

Facilitator – *When you visit the doctor, have they fully described to you the details regarding the problems?*

Grandfather – *They did talk to me but I never understood the situation and what they mean.*

Tongan grandfather

This caregiver's granddaughter has Down syndrome. There is no Tongan equivalent term for this syndrome and the condition is often referred to using a transliteration of the English word mongol, due to the characteristic facial expression of children with Down syndrome.

A major concern found in the study is the almost universal lack of understanding amongst the elderly caregivers surrounding the illnesses and disabilities of their charges. The elderly Tongan grandfather quoted above was a very conscientious caregiver. He had trouble keeping up with his granddaughter but made sure she was safe from significant traffic hazards that adjoined their house. The study found an overwhelming sense of duty and dedication. But getting run over by a train or car are not the only risks posed to a three-year-old child with Down syndrome. Such children are at risk of a range of health and developmental complications, some of which are not obvious, for example congenital heart problems, and hearing problems due to glue ear (which has greater prevalence among children with Down syndrome). Early detection and intervention can improve these children's future quality of life, but this relies on caregivers knowing what to do, when to seek help, and getting support from the right professionals at the right time.

I did my best in looking after my grandson and after two weeks, a social worker [probably a nurse] visited and taught me in a lot of ways how to look after him, like looking after his feet and lying him down.

Tongan grandmother

Even with medical conditions like asthma and/or eczema there were distinct limitations surrounding caregivers' understanding of these conditions and their appropriate management. One participant, when discussing their management of an asthma attack, stated:

The baby has an attack, what I usually do is I ask her to take the baby outside to get some fresh air.

And when asked 'what if it is cold outside?' her response was:

We have got a shed, he can still go outside. We have got the medicine there but it doesn't really help.

Clearly this Cook Islands Māori grandmother is actively intervening in a way she believes is in the best interests of her grandchild who is having an asthma attack. The responsibility for informing her that cold air makes asthma worse, and that the inhalers actually do work, falls on the health system. It appears from participant responses that the necessary information regarding medical conditions is not being given in a way they can absorb and understand.

The more complex the medical problem, the more information is required and the more difficult it gets for elderly caregivers.

Yes, my grandson speaks well but we know that he have polio as sometimes it is difficult for him to speak. He speaks well like, 'Nanna,

something wrong with my head’, ‘Nanna, my chest’. There was no one to talk to. One of my cousins who also has a polio child told me that my grandson should have this and that.

Tongan grandmother

The above quote is from an elderly caregiver whose grandchild does not in fact have polio but has shunted hydrocephalus, requiring multiple ventriculo-peritoneal shunt revisions involving complex neuro-surgical procedures and many admissions to hospital. This caregiver does not have a clear idea of the nature of the medical diagnosis and required treatments. This is likely to pose difficulties for her in engaging with health and support services, thus adding to her stress and potentially resulting in less than optimal treatment and support for her grandson. It is unknown whether this situation will be detrimental to the care of the child but it is far from an ideal situation.

4.4.1 Fear and anxiety

It was when she was about one year old when my granddaughter started suffering from epilepsy. When my granddaughter was diagnosed with epilepsy it was difficult for us to handle. This illness really scares you because when she has seizures you just don’t know what to do just putting her in cold water then we go to the hospital.

Samoan grandmother

A grand-mal seizure is a frightening event to witness. It is easy to appreciate the apprehension that anyone must experience if caring for a child with epilepsy. When all the complicating factors of being an elderly Pacific caregiver are thrown into the mix – transport issues, language problems, poor physical health (including the lack of strength to lift larger children), lack of information, and financial issues – this inevitably adds another distressing dimension when dealing with medical emergencies. The anxiety is an ever-present reality for the participants who care for children or young people with medical problems that can lead to medical emergencies as this elderly caregiver reports:

I get scared as a grandparent – I don’t want him to die.

4.4.2 Interpretation of advice

Another small but important finding was how literally the elderly Pacific caregivers took the advice from health professionals. When given dietary advice from the doctor many of the participants would not deviate from the advice given and became very rigid about what the child could eat, particularly when in the care of others. What is difficult to explain is why some information is acted on in a very rigid way and other, just as important, information (for example medication compliance) is not acted on at all. The emphasis must be on improved communication between health and social service providers and elderly Pacific caregivers.

4.4.3 Confusion about roles of health professionals

A common finding in the study was the marked but apparent confusion the elderly Pacific caregivers had surrounding the roles of the various health professionals involved in the care of the children or young people. In some cases it makes little difference to health outcomes but it is easy to see how difficult it would be for these caregivers to arrange appointments and contact the appropriate people within the health system if they did not know who was who.

For example, one elderly caregiver talked about the social worker visiting to help her grandson with his speech – a highly technical skill which would have been undertaken by a speech-language therapist.

My grandson was not speaking until the social worker came. Most times they converse in English and use sign language but my English is not that great.

Tongan grandmother

At times, too little time is taken to explain roles clearly to elderly caregivers. In the situation below the Tongan grandfather's grandson had been in the care of mental health services for three years.

Facilitator – *Do you know the difference between the psychiatrist and the clinical psychologist, did they really explain it?*

Grandfather – *No, not really.*

Facilitator – *Do you know what the psychiatric nurse... do you know what her job is?*

Grandfather – *Not really.*

Facilitator – *And what about the mental health social worker what is his role?*

Grandfather – *A little bit.*

Facilitator – *What do they do, what is that person's job?*

Grandfather – *I thought they monitor my grandchild's condition, or problem.*

Facilitator – *How does the social worker differ from the nurse and the psychologist, do you know what the differences between their roles are?*

Grandfather – *No not really.*

Medical systems are complex and this example illustrates that for elderly Pacific peoples, navigating these systems becomes even harder when the roles and responsibilities of the professionals involved in the care of the children or young people they are responsible for is not clear.

4.5 Theme five: Access

Participants' reports indicate that few are accessing the right services and information at the right time, or receiving all their available entitlements. This is not a surprising result and is consistent with national data regarding Pacific peoples' access to health and social services.

4.5.1 Accessing health services

Pacific children have higher hospitalisation rates (compared to non-Pacific, non-Māori children) for multiple diseases, including respiratory diseases (2.5 times higher), asthma (3 times higher), cellulitis (5.5 times higher), gastroenteritis (1.3 times higher), dental conditions (3 times higher), kidney and urinary infections (over 2 times higher) (Ministry of Health 2004). Children or young people with chronic illnesses or disabilities are likely to account for a large proportion of admissions. This was clearly the experience of the study participants who spoke of frequent and at times frightening emergency trips to the hospital.

The other sentiment reported by participants was their feeling that although many services were available, no one provider had oversight of their health needs and there was no co-ordination of the various health and support agencies; this led to their feeling isolated and marginalised by the health system.

Mother – We feel isolated from everything... it's just so new to us we never knew. We just feel, we just feel... well for me I just feel like we are on this road like you know, no one is stopping to help. Well obviously with my family and my family is here and it has helped me a lot, we are not getting the help or the support of the Ministry. You know we do get it now and then but it is not... it is only limited.

Grandfather – We have been kind of bouncing from one agency to another.

Niuean family

4.5.2 Access to information

The elderly Pacific peoples who participated in this research cared for a group of children and young people who had a range of medical conditions that necessitated information to be imparted in a manner that they would understand and retain. Regardless of whether it is a common condition like asthma, which has the potential to be life-threatening, or a very rare congenital condition, the better the medical information given the better are the likely outcomes for the care of that child. In almost every case the degree of understanding that elderly Pacific caregivers had regarding these conditions was poor.

But when I came to really understand what the doctor was saying that she has a condition or an illness and it's called ... it some kind of syndrome and that is opposite to Down syndrome, and I actually haven't looked into it exactly what it is to see what it is, all I wanted to do was to have my hands on her and to care for her, and in doing so I have realised that she is not quite like my other grandchildren, like her body was really soft and she didn't have the strength when you go to lift up a child you know, but she didn't, and so I accepted what was wrong with her, to a point where I actually wanted to look after her myself.

Tokelauan grandmother

What lies behind this phenomenon? Language is clearly a major barrier. The more fluent in English the elderly caregivers, the better informed they appeared to be. This was particularly evident across the ethnic groups, with the Tongan participants having the least English fluency and appearing to have the least medical understanding of the conditions and the least knowledge in relation to the health and social services available and how to access them.

It is also important to note that the elderly Pacific caregivers relied heavily on family members to provide the necessary information to care appropriately for the young people in their care, but even younger family members with good English literacy have difficulty getting the information they need from the health system.

Facilitator – *Did the doctors explain to you well what syringomyelia was and do you understand what the condition is now?*

Mother – *No that is what is upsetting to me. That is the most upsetting part of the whole thing...is that they didn't. They never explained to us*

at all what it was (mother became tearful at this point) that is pretty much what we've got.

Niuean mother

The child of the mother quoted above is cared for by the grandparents; if the mother has difficulty understanding the condition then her elderly parents are likely to have even more difficulty.

Almost all the caregivers were reliant on either their doctor or their family for information. With the exception of one caregiver, they did not use the internet (a rapidly growing source of information for the wider New Zealand community) and were hesitant about attending workshops or public forums, thus contributing to the further marginalised position they hold.

I have bottled up these feelings inside me for so long, and I never share with anyone what I'm going through, sometimes I was invited to attend community groups, I would prefer to borrow pamphlets and booklets and read about it or just ask my family doctor. Before there was no problem, but now with epilepsy and his weight it's very hard to handle him.

Tongan grandmother

4.5.3 Accessing support services

The sentiment expressed in the quote below is fairly consistent with how all the participants felt in their dealings with social service agencies.

There are times when I don't bother with WINZ I would seek help from my family to give me some money to help me with what I need because the time it takes.

Samoan grandmother

This applies to HNZC, WINZ, Accident Compensation Corporation and Child, Youth and Family. The pertinent issue is that elderly Pacific caregivers, for cultural and practical reasons, are not in a position to strongly advocate for their needs. Cultural considerations

include: a cultural bias towards not wanting to embarrass themselves when talking with authority figures and showing ignorance; extreme sensitivity towards being treated badly by authority figures and therefore not asking questions or being assertive or challenging in case they were ridiculed; and not wanting to be seen as ‘dumb’ as they couldn’t speak English properly or should have understood better.

Practical considerations include: fatigue due to advancing years; a higher number of medical problems; transport issues; language difficulties and difficulty comprehending; and filling in multiple forms. Despite these obvious limitations it is interesting to note that few, if any, special considerations are given for this vulnerable segment of the population by the very agencies that are designed to cater for their increased need. A dedicated customer service representative allocated to the elderly should be adopted by these various agencies as a simple and effective measure to address this issue.

The other important aspect of care is accessing resources, particularly for disabled children or young people.

My younger sister works at a hospital with children like my grandson and we talk as she always comes home and she told me that the Government supports these children. She sees that I am now 65 and I still lift my grandson into bed and would do with some help in showering and things like that.

Tongan grandmother

Pacific peoples are often finding out about entitlements from family members after long periods of delay because they are not aware of the services available; this is reflected in their uptake of fewer needs assessments than non-Pacific, non-Māori disabled people (Ministry of Health 2004).

The participants were also hesitant to access respite services, which is part of the funding package available to support caregivers of both disabled and chronically ill children.

One day ... we arranged with [the] social worker to take my grandson from Friday and I pick him [up on] Sunday so I can have time for this wedding. I came to pick him up and he was standing outside on his own. Staff were playing cards and other people were watching movies. My grandson was under a tree on his own, when he saw me he ran shouting, 'No more Nanna, no more Nanna'. I asked why he stands on his own under the tree and he was told to go there as he was having a bowel motion. I do not like arguing with other people and departments and I asked the nurse if I can use the bathroom as my grandson is dirty. She gave us a towel and I cleaned my grandson.

Tongan grandmother

Respite services are an important part of the total resources available to caregivers and can give welcome relief. There was genuine hesitancy in most of the participants about respite facilities; this appears to have both a practical and cultural basis. Hesitancy appears to be due to lack of trust in other caregivers and the strong relationship they themselves have with the children in their care, as well as to negative experiences with respite. These types of negative experiences are a major stumbling block and it is not in the belief system of Pacific peoples to hand the care of loved ones over to non-family members.

4.6 Theme six: Traditional beliefs

The participants demonstrated an interesting mix of both Western and Pacific beliefs in relation to illness and disability causation.

... when he was born he had a big head. Then they would say maybe the father ate pig heads and that is the first thing that comes to people's minds, he stole the pig ... that's why the head is like that, that's the island attitude and that's wrong.

Samoan grandfather

The appearance of a congenital defect, illness, or disability in a family member is often considered in many traditional cultures to result from some form of transgression of 'tapu' (sacred taboo) committed by parents, extended family and perhaps community. Causation is not confined just to the living, but can be wrongs committed by members of the family long deceased, as succinctly described by one of the participants:

To me, when I saw what happened, I was ashamed; however, who knows, it may have happened in the past generations up to now, then came a time to go to church and I noticed that the people are kind of laughing at her and making fun of her. So I did not want to go to church anymore. I prefer to stay home with her and look after her there. I felt that I'm going crazy when I hear people making fun of her and throwing remarks that it's a curse... I feel like punching and giving that person a hiding right there and then.

Tongan grandfather

It is important to understand the role that stigma (if strongly negative attitudes are held) may play in the lives of Pacific caregivers because it is relevant to the quality of care afforded young people, as well as to the increased isolation the caregivers may experience.

All participants in the study were well versed in the notions of breaking tapu and all were well aware of the strongly held traditional notions of the causation of sickness or illness. There seemed to be a variation between the focus groups and individual interviews concerning these beliefs. All the focus group participants admitted to knowledge of these

beliefs but distanced themselves from holding these beliefs. In comparison the individual interview participants were more open to saying they still held these beliefs. A question mark surrounds whether this distancing effect was a result of focus group members not wanting to be seen to be holding onto ‘old’ and perhaps questionable beliefs, and the individual interview participants not having to be concerned about the opinion of others and hence speaking more freely.

The important point here is that traditional Pacific beliefs about illness causation are still strongly acknowledged and probably held by most Pacific peoples of this generation.

I was saddened when one of my lady friends asked me, what have I done that causes my son to have that disability...

Tongan grandmother

Despite the prevalence of traditional views, participants were also comfortable with biomedical explanations – such as genetic disorders, hereditary, viruses and so on – being the explanation behind their child’s illness or disability. This ability to hold two competing views is not uncommon in Pacific peoples, as this Western-trained medical practitioner explains.

It is funny, even though we don’t believe in demons, we still would not sleep in the hospital overnight when there are dead bodies around. We get the training, but we still wouldn’t sleep there at night.

Poltorak 2004

In this regard, the gentleman quoted earlier in this section who said: “I did not want to go to church any more. I prefer to stay home with her and look after her there. I felt that I’m going crazy when I hear people making fun of her and throwing remarks that it’s a curse”, is deeply affected perhaps by the notion that he himself holds such beliefs and consequently is even more deeply affected when others suggest the same. The sadness for him however is that he is being prevented from attending a major social and spiritual institution in his life, because he is unable to manage the hurtful comments he is

bombarded with. This elderly caregiver certainly was not alone amongst study participants in feeling the discriminatory effects of these still widely-held traditional beliefs, but not all were as adversely affected.

4.6.1 Discrimination

Discrimination as a result of the child or young person's condition is an important issue for elderly Pacific caregivers. As mentioned above, the impact is felt differently depending on the circumstances and attitudes of the caregivers themselves. What there is agreement on nonetheless, is the pervasive nature of traditional views surrounding illness causation in the wider Pacific community; this was felt strongly and came from all parts of the community including the church. Church played a major role in the majority of the participants' lives and, although it was mainly a centre of support, it was also a cause of distress and embarrassment for some.

This contradiction lay with the fact that their spiritual lives and faith in God provided a major source of comfort and strength that enabled many people to cope with the stress of their lives. The distress and embarrassment was a result of the attitudes and behaviours of other parishioners in their church. The types of accusations directed at elderly caregivers and families with sick or disabled children or young people include such derogatory comments as marital infidelity or incest; this is consistent with the literature on the topic. (Ingstad 1990; Scheer and Groce 1988). However, the majority of participants had distanced themselves from these traditional beliefs of causation.

4.7 Theme seven: Traditional treatment

Elderly Pacific caregivers still hold very strong culturally-bound beliefs in the potency of traditional treatments for disease or illness, which is behaviour consistent with that of other traditional societies (Groce 1990). The dilemma they, and by default the children and young people in their care, face is making appropriate choices when confronted with medical problems. This debate is relevant regardless of the medical condition, but traditional treatments tend to be sought for less severe or non-medical emergency type clinical conditions (eg, eczema, skin infections, behavioural problems, mental illness). The important consideration is whether choosing a traditional treatment makes the health outcomes for the child or young person less optimal. The study participants were reticent about disclosing whether they used traditional treatments but were aware and comfortable with the knowledge that many of their compatriots did.

There is no accurate statistical information quantifying the number of active Pacific traditional healers operating in New Zealand and how many consultations they undertake, but anecdotal evidence and comments from the participants indicate the continuing significance of traditional healers in the New Zealand Pacific community.

Facilitator – Are traditional beliefs and traditional treatments still strong amongst the Tokelauan community in your experience?

Tokelau caregiver – Yes, yes, that is very strong still. They seem to believe that something has caused the sickness. So they will look for someone to cure that sickness in the sense of calling on to some ancestors to come and do the massage and things like that to the point where they even talk to the dead and ask them you know ... and we know it is not real so.

Facilitator – This is a very pagan practice not a Christian one but yet all our communities are very Christian but we still practice some very pagan rituals – can you comment on that ... why?

Tokelau caregiver – I guess... I myself will never go there although I have seen it and the people who actually perform massage believing in that. My personal discovery is that they don't really

know or understand who God is the creator and so they kind of believe what they hear and see. So they follow the old beliefs by saying 'oh yes because he did something and the ancestor is there' so they go and talk to them and seem to be more on that side. Rather than coming away from that.

Despite this evidence of strongly held traditional beliefs it is not known what impact this has on the care provided to the children and young people they are responsible for.

4.8 Theme eight: Emotional dissonance

The range of emotions experienced and expressed by the elderly caregivers covered the entire available spectrum. Powerful emotions were conveyed and arose from the difficult circumstances they faced. What follows is a presentation of the data as it pertains to these powerful emotions so that conclusions can be drawn on how to enhance the positive and negate the negative elements of emotion in the lives of these caregivers. The reason that this section is entitled 'emotional dissonance' is that many of the emotions expressed by the participants and described below are felt either simultaneously or at different times during their tenure of care, but are often in conflict.

4.8.1 Love

There is no doubt that the single most important driver behind the actions of participants involved in the study was love.

*So he needs someone with love and patience, love and patience.
Love is there right from day one when we found out.*

Niuean grandmother

This caregiver reported that all her family have drawn closer as a result of the condition affecting her grandchild. This sentiment is echoed by other participants.

Our child has been a blessing to us and has brought our family much closer together.

Samoan grandmother

The families that were drawn together by their love for the children or young people in their care with a chronic illness or disability appeared to be managing better overall.

Our family sort of decided to change our lives. I've got a sister who decided to take up massage therapy to try and help him as well. In order for us to deal with this condition that we did not know anything about you know that's the hardest thing, you know we just took it and we just ran with it and we never looked back.

Niuean mother

4.8.2 Pride

Pride and shame are different sides of the same coin. One of the most striking features in the participants was their deep sense of duty and commitment to the young people in their care and the dignified manner in which they carried not only themselves but their burdens as well.

Good at this point in time this pathway which we're in now is not new to me. I look at the things in the past. I said to them please listen and in my opinion I am not like those who are quick to ask for money and that can be a contention in a home but for me I have never asked for money.

Elderly Niuean caregiver

The elderly Niuean woman quoted above cares for a severely disabled and at times very disturbed daughter with paranoid schizophrenia. Her daughter's child with an intellectual disability, who is now 18 years of age, has been cared for from birth by her grandmother. They live in a HNZC home and were very poor, yet during the interview this caregiver was concerned about the state of the economy and believed they could manage on the money given to them by the Government. She felt that other people would be more deserving of assistance and was accepting of her situation.

This sentiment was common amongst the caregivers and probably reflects not just a sense of pride that they can and will make do despite difficult circumstances, but an acceptance of the position they find themselves in despite their conflicting feelings.

4.8.3 Guilt

All the elderly caregivers in the study had other grandchildren. They almost all expressed concern, remorse and even guilt at the lack of attention, time and energy given to the wider circle of grandchildren as a result of caregiving for the sick or disabled grandchild in their midst.

Another issue that occurs in our family is that our other grandchildren, as we have three grandchildren who are all boys, will at times think we love our disabled grandson more than them.

Samoan caregiver

There appeared to be a stoic, practical acceptance of this state of affairs, with caregivers knowing there was no alternative apart from prioritising their efforts and getting on with it. From a Pacific perspective however this is far from ideal and is a psychological burden that can add to the distress that vulnerable elderly Pacific caregivers experience.

4.8.4 Shame

The perspective of Pacific families regarding children born with congenital defects or who develop chronic illnesses is related to whether they take a sympathetic or indifferent stance towards the care of their child. It is the chronically ill or disabled children growing up with those elderly caregivers who maintain the traditionally negative views of sickness or disability who are at greatest risk. Such caregivers are more likely to be embarrassed and ashamed of the child and therefore more likely to consider the child a burden on the family and their presence not welcome (Rengill and Jarrow 1993).

... I guess I would say that there is a mixture of sorrow, shame and regret... I just can't admit to anyone the problem is Down syndrome, even my family, I didn't have the courage to let them know.

Tongan grandmother

There were also many instances of difficult situations that arose from the day-to-day activities involved in caregiving which created shameful situations but differed from the shame of having a child born with a disabling condition. For example, a 69-year-old Tongan caregiver was a very dignified gentleman who had become tired of the repeated school visits to the principal as a result of the activities of his grandson with ADHD.

Very shameful, very shameful, going there, the principal, teachers and students... staring at me.

Tongan grandfather

Despite limitations in many areas the children in the care of the participants were mostly well cared for and appeared from the data to be actively engaged within wider families and communities. The caregivers sometimes experienced sadness when other people or children teased their loved ones.

No I didn't, and I couldn't stop crying, but I guess that sorrow brought about the understanding and to accept the truth of the matter, but still at times there are certain things that triggers the pain and it still hurts deep inside, especially when I saw him playing with other children, and those children often mock him.

Tongan grandmother

4.9 Theme nine: Spirituality

In English the word 'spirit' comes from the Latin *spiritus*, meaning breath but also 'soul, courage, vigour'. However spirituality is defined, conscious spiritual awareness was deeply ingrained and clearly part of the fabric for all elderly caregivers taking part in the study. Critical examination of the role spirituality plays in the lives of elderly Pacific caregivers (as expressed to the research team) requires division into three parts: firstly, their own personal subjective experience; secondly, the institutional religious component that they participate in with its ever present social forces and expectations that colour their personal experiences; and, finally, a dissection into the various functions that spirituality performs, analysing for both positive and negative outcomes.

Culturally with us Samoans we have faith in God that he is able to heal any illness.

Samoan grandmother

4.9.1 Subjective spiritual experience

Attempts at theological explanations can sometimes fail to capture the human experience of spirituality. Sometimes the most informative descriptions are captured by listening to those that have the most need for spiritual comfort.

When I wake up every morning and while I look up, I see the ceiling and I think oh thank you Lord that I am alive. You have given me another day and so that's the way I cope. I say well Lord I don't know what today's going to bring but you know please give me the strength, please give me wisdom, please teach me to be patient. So I find God plays the major part in my life and I call on him all the time and not only that I share if they like to what Jesus says to me and I read the word of God and I you know I like to sing at times, you feel so down, oh well okay then I will sing this song and then you know it boosts your strength again you know. Admitting to the Lord I don't know what to do and I really don't feel like doing ... but help me because this is a child here that needs you Lord and needs me but you know I can't help her if I don't have you.

Tokelauan grandmother

The personal circumstances of this participant included the care of a child with a rare congenital disorder as well as significant health problems in her adult children. Her personal experience of God in her life as relayed during the individual interview conveyed a sense of deep personal relationship, leaving the impression that God was a physical presence in her household.

This sense of personal relationship with God and a sense that God was an active not passive participant in their lives came through strongly with all the participants. Their experience of spirituality was clearly linked to their early childhood experiences which went hand-in-hand with the development of their 'duty of care' philosophy.

I was very close to my grandmother and I saw the way that she looked after all of us and also I saw her spiritual life like that's how I knew who Jesus is and I see her pray every morning early in the morning and I being the oldest grandchild so I was always by her and she came here she actually cared for the whole family.

Tokelauan grandmother

It is highly likely that caregivers' 'duty of care' philosophy became deeply ingrained through a combination of their early childhood exposure to their 'aiga' or family caring for each other and the religious teachings of Christianity.

4.9.2 The role of organised religion

No treatment of the challenges that elderly Pacific caregivers face raising children or young people with chronic illness or disabilities would be complete without analysing the role of organised religion. The introduction of Christianity in the mid-1800s had a profound effect on the social organisation and ideological constitution of Pacific culture.

The institution that is the Christian church has promoted a subtle but significant shift of emphasis within the traditional Pacific kinship system, strengthening the smaller units of social organisation (the nuclear family) at the expense of larger kinship groups (Evans 2001).

This shift has had a dramatic impact on elderly Pacific caregivers in the New Zealand context. In simple terms a large functional kinship group would either find alternatives or provide more support for elderly caregivers who would be called upon as a last resort. The striking feature of this research is why such a vulnerable group of people is being called on to care for children with such complex and demanding needs? The answer is that there is nobody else available.

A balanced view of organised religion suggests that people continue to be active participants only if certain needs are being met. Otherwise they simply stop participating or move, as is often the case, between same-faith churches or different Christian denominations. The participants in the study were all Christian and almost all were active attendees of organised Christian groups of varying denominations. The sentiment that involvement with the church and church attendance was psychologically beneficial was often recounted.

Oh yes I pray every night asking for help like calm, it does help you know when you kneel down and pray and I think God helps me with the children and we ask even to understand so that we won't be so depressed and we take the children to church every Sabbath and we go to church and sit there and listen to the singing at the service and that takes your mind off everything. Off your daily problems and daily stressors.

Tahitian/Tongan grandfather

Considering the act of attending church from a sociological perspective, the gathering together with other people is an important social function. The position that elderly Pacific caregivers find themselves in results in fewer opportunities for social interaction with peers and the wider community – hence the greater need for the social interactions found through attending church.

The benefits of church attendance and participation are therefore clear-cut. Nonetheless there are certain aspects of church involvement that can be stressful. As discussed earlier, active church involvement often comes at financial cost, with other difficulties being stigmatisation and accusations of familial fault from parishioners.

One thing is the church culture and customs and things like that, whatever part of that custom that would come into the family, they would have to give money, even though they know that the money is to pay the rent and to pay for power and to put food on the table, they will still have to keep within this custom and culture. I have experienced this a lot.

Tokelauan grandmother

Involvement with organised religion has many benefits for elderly Pacific caregivers but also comes with certain drawbacks. In response to this situation a conversation needs to be undertaken within the Pacific community to address the issues of remittances, negative traditional beliefs and discrimination.

5.0 Discussion

The results of the study indicate that elderly Pacific caregivers are a small but very vulnerable group in New Zealand society. They have been forced to take on the role of primary caregivers for children and young people whose complex medical problems place a burden of care that in many cases they are poorly prepared to manage. It is a mark of their resiliency that they cope as well as they do. What makes these elderly Pacific caregivers so resilient?

The answer to this question is multi-factorial and a full analysis is outside the scope of this particular piece of research. However, resiliency is dependant on functional coping strategies (coping being a general term that refers to the actual strategies individuals use to manage stressful life events). It was abundantly clear from the data that the most common strategy employed by elderly Pacific caregivers was spiritual and religious in nature.

What is within the scope of this project is acknowledging resiliency as an important quality in elderly Pacific caregivers. But more importantly: what actions need to be taken to reduce the degree of burden that they are forced to carry? The most effective means of reducing this burden is by making special provision to ameliorate the social and economic factors that exponentially increase the difficulties they face.

Before this can be done there must clearly be a method or system developed for the identification of elderly Pacific caregivers so the extra supports they require can be put in place. If this can be achieved the study findings indicate that the adverse socioeconomic conditions affecting these elderly caregivers can be addressed. For example, a very effective means of directly ameliorating the detrimental effects of poverty is cost-effective housing. Providing preferential access to low-cost and suitable housing for this vulnerable group would strengthen their financial position significantly, create stability in their lives, and improve health and wellbeing for both the elderly caregivers and the children/young people they are responsible for.

It has been shown that providing adequate housing ameliorates the likelihood of suffering from an array of physical and psychological problems. Poor housing conditions are a significant risk factor for many common health conditions and the most at risk are the young and the old. Damp conditions, mould, temperature extremes, fewer material resources and overcrowding are strongly correlated with meningococcal disease, rheumatic fever, TB, bronchiolitis and croup in children (Baker 2000; Baker and Howden-Chapman 2003) and respiratory disorders and mental health problems in the elderly (Gray 2001).

Elderly Pacific caregivers have less access to home ownership (Ministry of Health website 2009), resulting in housing instability. If elderly caregivers are required to move because of unstable housing arrangements they are forced to move away from their relationships with social networks, family, schools and health providers. Having to re-establish these relationships is difficult for this age-group. In addition, they may not be landlords' prime choice of tenants and are therefore less likely to get decent accommodation in the private sector.

The added complication for many participants was their own level of able-bodiedness. For example, housing options are further restricted for elderly people as a result of not being able to access some boarding facilities, apartments, high-rise blocks, or two-storey houses on slopes. At this late stage in life they would never be in a position on their own to save a deposit or pay a mortgage so would remain trapped in the rental cycle.

One of the ways that Pacific families combat the costs associated with housing is to live in larger numbers in the one property, sharing costs; 47.5 percent of Pacific children aged 0 to 14 years are living in overcrowded conditions (Statistics New Zealand 2003). Elderly caregivers living on their own who participated in the study were significantly financially worse off than if they were living with other family members. This makes rational sense and is consistent with international findings in the disability sector, for example Canada where living in households with other people reduced poverty from 45.5 percent to 16.5 percent (Fawcett 1996).

It is widely recognised in the international literature that people with disabling conditions experience high rates of poverty and have limited opportunities, increasing their dependence on social programmes (Reference Group on Welfare Reform 2000). What has not been widely recognised is the impact disabled children and young people have on the independence and financial security of those required to care for them, especially if they are elderly.

Finally, a discussion on the impact of poverty would not be complete without a discussion of the opportunity cost to elderly caregivers as a result of caring for children or young people with a chronic illness or disability. With the limited finances available to them they are being forced into constantly having to choose between purchasing needed health- or disability-related items and other necessities of life. Something has to give and it is areas such as personal material items, personal travel, and more expensive cuts of meat or particular dietary preferences or social outings that are relinquished. Although it was not explicitly stated the research team inferred that the care of the child or young person took precedence over the health needs of their caregivers.

Placing the needs of the child or young person before their own is not difficult to understand and speaks to the love, sense of duty and commitment that elderly Pacific caregivers have towards their families. Unfortunately their advancing years bring with them a series of age-related health problems that adversely affect their ability to provide care for others. Common conditions of old age are numerous, including (ranked in order of prevalence): coronary heart disease (with related blood pressure and cholesterol factors), stroke, diabetes, cancer (especially lung, colorectal, prostate, breast), dementia (and other neurological disorders such as Parkinson's), and arthritis. Other conditions that can be just as debilitating include frailty, falls, osteoporosis (leading to hip fracture), pneumonia and influenza, incontinence, depression, social isolation, visual loss (cataract, glaucoma), hearing loss, and chronic respiratory disorders (for example, emphysema).

Pacific peoples experience poorer overall health and have a lower life expectancy compared with the total New Zealand population (lower by 4.8 years for men and 4.2 years for women) (Ministry of Health 2008a). The high incidence of medical problems

amongst the participants in this study is therefore likely to be highly consistent with elderly Pacific peoples as a whole. Caregivers place the wellbeing of the child in their care before their own, putting an already at-risk group at an even higher risk of serious health outcomes that would not be in the best interests of either themselves or the child or young person they care for.

The study findings also indicated varying degrees of social isolation experienced by the elderly caregivers, which the literature indicates is bad for their wellbeing. Numerous studies indicate increased physical problems such as coronary disease in elderly people living alone (Lett et al 2005), and the evidence suggests that simple interventions, like elderly support groups, that reduce social isolation, improve biochemical markers of health in a short space of time (Arnetz et al 1983).

The participants who were more socially isolated tended to have a lower standard of housing and a higher level of stress, and generally were more emotionally changeable when interviewed. Their overall mental state was therefore negatively impacted, which meant that the quality of care they were providing was poorer; the indication is that increased social isolation leads towards poorer quality of life outcomes for both caregiver and child.

Compounding the poorer health status of elderly Pacific caregivers is the evidence that Pacific peoples are differentially treated by the health system. For example they are less likely to be referred to specialists (20 percent vs national average of 30 percent), with access to surgical care particularly problematic. Pacific peoples with disabilities are also less likely to have received a needs assessment than their non-Pacific peers (Ministry of Health 2004). These problems plus other pertinent issues facing elderly Pacific caregivers must be addressed.

One of the most important issues is the lack of understanding that elderly Pacific caregivers have in relation to the often complex medical problems experienced by the children and young people in their care. The provision of information is not simply a

function of language but a function of good communication and relationships, ensuring information is understood and given in an acceptable manner.

This is a growing area of interest because the evidence suggests that improvements in cultural competence in the New Zealand health system should lead to better outcomes through improvements in communication. This should lead to increased understanding, and therefore increased acceptability of Western treatment approaches and adherence to treatment plans, resulting in better health outcomes for the people involved (Crengle 2000; Krupat et al 2001). If elderly Pacific peoples are more informed this will lead to more insightful choices made about when to use traditional versus Western treatment options.

The implication is that the health system interacting with these elderly Pacific caregivers needs to pay greater attention to ensuring they have the necessary information, and understand it sufficiently, to address the health needs of the children in their care and keep them safe. This is a health literacy issue, and improving the ability of the health sector to enhance health literacy is an important objective. The complexity and the changing medical needs of the children and young people cared for may require special advocacy and support services that elderly Pacific peoples can access. These services could be delivered via Primary Health Organisations (PHOs) and/or Health and Disability Support Services.

Additional effort must also be directed at addressing the ongoing stigma and discrimination that elderly Pacific caregivers face from traditional beliefs still held by the Pacific community. The idea that sickness, disability or unwellness results from a curse as punishment is well documented in Pacific ethnography but there 'must be legitimate causes for the curse such as breaking of an important tapu and so on' (Bloomfield 1989). The participants had distanced themselves from this traditional notion but suffered when confronted by accusations of familial misdoing as the cause of illness or disability within their families. Shifting these attitudes is important and the most effective method would be engaging the Pacific communities using prominent Pacific persons, Pacific media and the church.

Elderly Pacific caregivers face many challenges, with the research findings indicating the health and social status of many of these caregivers is adversely affected by the responsibility of caring for young family members with chronic illness or disability. Following the concluding comments in the next section, the detailed implications of the research in section 7 indicate what could be done in response to the challenges outlined.

6.0 Concluding comments

The first requirement was for this piece of research to illuminate the areas of inquiry outlined in section 2.

The first requirement was to ensure the study design allowed for the gathering of stories from elderly Pacific caregivers, and allowed for their cultural contexts to be considered without language barriers interfering. The study was to gather information from Pacific peoples, from a Pacific perspective, to enable critique of current assumptions about solutions for enhancing health and wellbeing for carers. The study was expected to identify the additional challenges for elderly Pacific caregivers and explore round the continuum of family caring, to inform and deepen the knowledge available to the health sector. The information gathered was also to increase the ability of the health sector to consider complexity and diversity when developing interventions to support informal carers, and in particular, the differential needs of elderly Pacific caregivers.

The study methods, personnel and analytical processes have delivered a data set that has allowed the research team to address the outcomes as stipulated. As in any research endeavour, there are strengths and limitations that impact on the overall quality and final outcomes achieved. These limitations are discussed in some detail in the appendices, but indications are that the findings are consistent with other information available in New Zealand and internationally and the research team conclude that the results are robust.

Overall the research project was a worthwhile and valuable endeavour as it identified very clear themes which were consistent in almost every case and therefore add to the claim of validity. The circumstances influencing why the elderly person was caring for the young person may have differed but the outcomes and shared experiences were similar in most cases.

Review of New Zealand's national strategy for its ageing population is recommended. Such strategies must not only assess the demographics of ageing and their implications for social and economic planning (Racic 1999) but also specifically address the unique circumstances of elderly caregivers from ethnic minority groups.

The study illustrates unique challenges that face elderly Pacific caregivers, including: language barriers; significant cultural preferences; poorer access to both medical and social services; a greater degree of illness, poverty and isolation; and perhaps less access to financial and resource entitlements as a result of not knowing how systems work. These considerations are even more pressing with the predicted increase in elderly Pacific peoples in the future. Statistics New Zealand predicts a rapid rise in the number of elderly Pacific peoples over the next four decades (68,000 elderly Pacific peoples by 2050) (Ministry of Health website 2009). The report goes on to say that:

Some social changes seem particularly significant in limiting the social well-being of Pacific communities. Housing conditions have worsened for Pacific families, with more crowding, a fall in home ownership rates, while a high vulnerability to diabetes may affect the quality of life of older people.

The stage is set for a rapidly increasing number of elderly Pacific caregivers over the next decade who will experience poorer quality of life by having to take on this role.

Without significant changes in the health and support systems available to them, and to the children and young people they care for, these caregivers will experience unnecessary and avoidable hardship. The implications that follow derive directly from the information gathered and are therefore both valuable and valid. It now becomes an issue of moral fortitude, political will and action to ensure that the right interventions are delivered to this very vulnerable group of people.

7.0 Implications

7.1 Strategic policy

Acknowledgement of the vulnerability of elderly Pacific caregivers must occur first at a health and social policy level within government, with their specific needs identified as a priority action area. If this is not achieved, health and social sector funders and planners at regional and local levels are unlikely to take the necessary steps to support this vulnerable group.

It is suggested that addressing the needs of elderly caregivers, with specific reference to elderly Pacific caregivers, should be made a priority action area by government agencies. The creation of an Elderly Pacific Caregivers Action Plan may be a way to achieve this.

7.2 Intersectorial collaboration

The needs of elderly caregivers, and in particular elderly Pacific caregivers, cross many state sector areas. The results of poverty and social marginalisation lead to numerous problems as identified by this study. Primary care, specialist care, and other areas of health, housing, benefits and needs assessment for both elderly caregivers and chronically ill and disabled children require extensive intersectorial collaboration. This type of collaboration has been effectively achieved in the Pacific disability sector by the establishment of Lu'i Ola as part of the recommendations from the Lu'i Ola: Auckland Pacific Disability Plan. Lu'i Ola is a major intersectorial working group, involving Pacific community leaders of disabled people; all the major government departments have signed a joint memorandum of understanding holding all parties accountable to the needs of disabled Pacific peoples as demanded by the national Pacific Health and Disability Action Plan. It is suggested that the needs of elderly Pacific caregivers be included in a reviewed strategic scope for Lu'i Ola. This could operationalise the strategic policy position of the Ministry of Health and is cost effective, because addressing the needs of elderly Pacific caregivers caring for disabled or chronically unwell children or young people aligns with the core functions of Lu'i Ola.

Lu'i Ola has been very successful in raising the profile of Pacific disability matters and improving the quality of services delivered to a similarly vulnerable and marginalised group. It is this type of intersectorial collaboration that must be brought to bear to effectively and efficiently assist elderly Pacific caregivers.

It is suggested that the Ministry of Health investigate the possibility of incorporating the needs of elderly Pacific caregivers in the terms of reference of the Lu'i Ola Working Group.

7.3 Improved access

The research findings indicate that access to health and social services is not ideal. Although the caregivers frequent primary care services their level of understanding of the complex medical conditions affecting the children and young people in their care is poor and their attention to their own health needs is also poor. They are unaware of the services available and the entitlements they can apply for. Usual methods of information dissemination will not get through to this group so an effective solution is one similar to that used in the disability sector – providing funding for information and advocacy support services for elderly Pacific peoples.

The health sector has PHOs that are funded to improve community access to health services. The disability sector has mainstream Disability Information Advisory and Support (DIAS) services and the Pacific Information and Advocacy Support Services (PIASS) that operate at a national level. One of these groups could be funded to identify elderly people providing care for chronically ill and disabled children. They already have the systems in place to undertake the identification process (as many of the children with disabilities will already be known to these agencies). Co-ordinators could be employed to assess caregiver's needs and actively co-ordinate the services they require (housing, benefits, medical attention, etc) and ensure that essential information is fully and completely understood (as far as possible).

It is suggested that consideration be given to funding Pacific PHOs or Pacific DIAS services to identify elderly Pacific caregivers nationally, and that these agencies be funded to employ elderly Pacific caregiver co-ordinators to assess and co-ordinate the services required. In the first instance, this could be piloted in a selected region with selected Pacific PHO or disability services providers, measuring the outcomes following a 12-18-month period. Evaluation could be both at a caregiver satisfaction level and quantitative measure of uptake of the new programme.

7.4 Service providers

Mainstream service providers need to become more aware and sensitive to the unique needs and cultural issues that impact on all aspects of service delivery to elderly Pacific caregivers and be responsive to their needs. The international literature recommends appropriate cultural competency training for all health and social service agency staff who come into contact with Pacific and indigenous people. The health sector is addressing this important area and the process has been dramatically hastened by the inclusion of cultural competency training as a mandatory requirement of professional health bodies. The New Zealand Medical Council is a good example of how this process can work. Their goal is to help medical doctors achieve greater awareness of the cultural diversity of Pacific peoples in New Zealand, and to assist them to incorporate cultural competency for Pacific peoples into their continuing education activities. This policy was instigated following the directive laid down by the statutory requirements of the Health Practitioners Competence Assurance Act 2003 (HPCAA). It is therefore suggested that cultural competency training is made mandatory for all government health and social support agencies and their staff.

In addition, a dedicated customer service representative allocated to the elderly in relevant support agencies would be a simple and effective measure to ensure their needs are not overlooked.

7.5 Further research

This research project highlights the dearth of research in New Zealand on the experiences of elderly Pacific caregivers and the poor quality of the information and technology systems which should be able to identify these individuals; quantitative data is required and these systems must be set up. In an environment of scarce health funding any further investment in research could focus on outcomes if the above suggestions are implemented.

7.6 Immediate attention

The implications of the findings as set out above will take time to action and in the interim elderly Pacific caregivers continue to struggle, particularly in the area of appropriate housing and accommodation. One immediate important action should be for HNZA to prioritise elderly Pacific caregivers when waiting lists are addressed. This must be established at a national policy level to ensure accountability by HNZA.

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9.0 Appendices

9.1 Study design

The National Health Committee (NHC) stipulated that areas of inquiry must include:

- experiences of caring for a young person with an illness or disability
- perceptions held by older Pacific people of their roles as caregivers in New Zealand
- key issues experienced by older Pacific people that support or compromise their ability to provide adequate care
- factors that compromise and/or improve and enhance the health and wellbeing of older Pacific informal caregivers
- approaches for promoting positive roles of caregiving and wellbeing for older Pacific informal caregivers.

(Ministry of Health Request for Proposal 2008)

9.2 Research methodology

9.2.1 Explorative qualitative study design

The study was specifically designed to answer the research questions outlined above. An exploratory qualitative research design was employed as the best method of understanding the ‘experiences and support needs of informal elderly Pacific caregivers who are caring for a young person with an illness or disability’. Qualitative research is a scientific method that allows the robust analysis of the meanings that people attach to their lived experiences and how they make sense of these experiences; this was therefore the appropriate research method to understand the experiences of informal elderly Pacific caregivers.

‘Informal elderly Pacific caregiver’ refers to an older member of a household, such as a grandparent or other extended family relative of that generation, who provides the primary caring role for a young person to whom they are related. ‘Informal’ also implies that the

caregiver is not paid for their services, in the way that a caregiver formally employed to care would be.

The main focus of the study was to obtain in-depth accounts from a number of primary caregivers. A primary caregiver is defined as the person who provides the majority of the young person's care, and who is normally living with that young person. In addition, information from wider family networks involved in caring, and members of the Pacific community surrounding the person, was sought.

The biggest challenge in successfully undertaking this research was navigating the complexity inherent in doing cross-cultural research. The tension exists at the interface of Western research methods and Polynesian culture. Cultural considerations were addressed in some detail in section 3 because these were central to the successful completion of this project. The extent these considerations were taken into account is evident throughout the report.

9.2.2 Recruitment

Vaka Tautua co-ordinates 10 Pacific elderly health and social support groups across the greater Auckland region, with a total register of 453 elderly people. Each of these elderly groups has a co-ordinator who approached possible participants for the study and notified the research team about interested parties. In addition, possible participants were drawn from the 2,085 Pacific peoples who are registered with the Pacific Information and Advocacy Support Services (PIASS – a parent trust of Vaka Tautua) and use the information and advocacy support services; and the 1,008 caregivers for disabled Pacific peoples who regularly contact the service. Finally some participants were drawn from Pacific PHOs in the Auckland area.

A total of 24 informal elderly caregivers took part in the research – eight participants in each of the Samoan and Cook Islands Māori focus groups and eight individual interviews. The ethnic breakdown of the individual interviews were four Tongan, two Niuean, one Tokelau and one part-Tahitian, part-Tongan elderly caregiver. Each participant was given

an information sheet (see 9.4.2) and signed a written consent (9.4.3) following an in-depth explanation of their rights in their language of choice.

9.2.3 Focus groups

The focus groups were conducted at the head office of Vaka Tautua. Focus groups are a form of group interview that capitalises on communication between research participants in order to generate data. The best method of conducting a focus group is to explicitly use group interaction to provide distinctive types of data. The participants are encouraged to talk to one another, ask questions, exchange anecdotes and comment on each others' experiences and points of view (Kitzinger 1994).

As part of the study design two focus groups were held with the Samoan and Cook Islands Māori communities as the two largest groups respectively amongst New Zealand's Pacific communities. Focus groups were kept relatively small as previous experience had taught the research team that larger groups prevented each participant from having a fair opportunity to voice their concerns. Groups were run as two one-hour sessions with a break in the middle, using a more semi-structured approach to the first hour (see 9.4.4), with each participant having an opportunity to answer questions. The second session followed the more interactive method described in the paragraph above.

Cultural considerations required a high degree of sensitivity surrounding: the opening and closing of the focus groups in a culturally appropriate manner; allowing time for in-depth introductions; giving sufficient time to answer questions; and giving each participant time to become comfortable with the other members of the group if they did not feel like sharing at the start. Following cultural processes, although time-consuming, created a sense of personal safety for participants that in the opinion of the research team led to greater participation and divulging of personal information. Best practice dictates the creation of a comfortable environment for focus group participants (Morgan and Kreguer 1997). The research team therefore put an emphasis on providing pastoral care for the caregivers including: payment for travel; a significant koha; refreshments; and regular

breaks during the interviewing. Favourable comment on these efforts was fed back from the participants at the conclusion of the groups.

9.2.4 Individual interviews

The research team made a conscious decision that wherever possible the individual interviews would take place in the homes of the elderly caregivers. Firstly because it was felt they would be more comfortable in their own surroundings and therefore more open, and secondly to experience first-hand the conditions in which these elderly caregivers were caring for their young ones.

Pacific principles such as the Samoan *va fealoaloa'i* (*caring for interpersonal relationships*) and the Tongan *feveitokai'aki* (*respect*), enable interaction with elderly Pacific peoples that is conducive to the interview process in that the participant is made to feel valued. These principles and others played an important role not only in the individual interviews but also in the focus groups and any interaction the research team had with the Pacific community.

Seven of the eight interviews were conducted using an unstructured qualitative interviewing style, with open-ended questions wherever possible, that fed off the content of the conversation. Best practice stipulates that good interview technique should involve questions that are open-ended, neutral, sensitive and clear to the interviewee and interviewers did their best to adhere to these principles; the ultimate goal being participants talking freely about their beliefs, attitudes, actions and behaviours (Patton 1987). From a cultural perspective the Pacific concept of 'talanoa' was the framework used to facilitate discussion in both the focus groups and individual interviews (Manuatu 2000). The final interview was a very structured affair as only one Tokelauan participant was involved and she was asked to comment from a Tokelauan perspective on the findings of the study to that point. This participant had been an accredited hospital translator and so had extensive experience working intimately with her community as they engaged with the medical system. For this reason it seemed appropriate to deviate from the unstructured classical type of qualitative interview adopted for the other participants.

This participant's insights and comments made a significant contribution to the overall data gathered. All individuals were given a koha (gift) in gratitude for giving their time and sharing their experiences with the research team.

9.2.5 Translation

All non-English interviews and focus groups were transcribed firstly into the Pacific language in which it was conducted. The World Health Organization (WHO) translation guidelines (WHO 2009 website) indicate that best practice involves a forward and backward translation undertaken by two separate linguistic experts, focusing on conceptual rather than literal translation, and then the degree of agreement/disagreement correlated. Due to cost restraints the translation process was limited to an initial translation undertaken by a fluent native speaker then checked by a second native speaker as a quality control mechanism.

Despite quality control attempts, there are inherent translation complexities as illustrated by the following example. The following Tongan quote reads as:

*Pea koe taimi koe 'oku mei kei hanga holo ai he fe'iloaki, kuo tangi hake hoku tokoua lahi mo ne pehe mai kiate au, 'aho moe po mo 'eku tangutu heni ho siofi kae toki ha'u pe ho'o mum pea 'oku ke **mulituku** kiai ho'o mo'ui eee....na'e fu'u **fakamamahi** 'aupito 'ae fo'i taimi koia... 'Io kei hoko koe 'osi 'ae manava.*

Two words are highlighted for analysis – *mulituku* and *fakamamahi*. The Churchward Tongan dictionary (Churchward 1959) defines *mulituku* as 'last dance, concluding song or dance or ceremony'. The translation reads as if the daughter waited for her mother to 'conclude' her life with her present. The word 'conclude' does not capture the intimacy and sorrow of the moment but makes little impact on the meanings or conclusions drawn. The word *fakamamahi* is defined as 'to cause pain or sorrow' yet the translation reads 'depression'.

If this translation is taken too literally as meaning this grandmother was ‘depressed’ by the events taking place, then inaccurate conclusions can be drawn. The question arises about what percentage of translated words and statements makes little difference to the analysis and what percentage leads to significant misinterpretations. Without doing an exhaustive linguistic analysis the appropriate response to the dilemma posed by the question is to undertake analysis in first language. This was not possible for each language, such that translation errors are an inherent but acknowledged limiting factor in the study and greater attention was paid to ensure individuals’ words are interpreted in the entire context of what was being said.

9.2.6 Analysis

Both focus groups’ input and all the individual interviews were transcribed verbatim. The Cook Islands Māori focus group and three of the individual interviews were conducted in English so did not go through a translation process. The Samoan focus group was analysed in first language by a Samoan cultural expert and the four Tongan participant interviews were analysed in first language by the principal investigator with the assistance of a cultural expert, hence avoiding loss of meaning and nuance that occurs in translation. The only interview where analysis in first language was not attempted was with one elderly Niuean caregiver, as we did not have access to a Niuean cultural analyst. Therefore this interview was analysed from the English translation. For the other Niuean participant the interview was conducted in English as this was their preference.

The intended goal of the focus groups was to bring the major areas of concern for elderly Pacific caregivers to the surface and then to use the individual interviews to explore these major issues in greater depth. This type of research process is known as sequential (Becker 1971) or interim analysis (Miles and Huberman 1984). This allowed the research team to pursue emerging avenues of inquiry in further depth. This culminated in the final interview seeking the opinions of the participant on the issues uncovered rather than interviewing using the classical totally unstructured technique.

Glaser and Strauss' 'grounded theory' guided the inductive process of coding incidents in the data and identifying analytical categories as they 'emerge from' the data (developing hypotheses from the 'ground' or research field upwards rather than defining them a priori) (Glaser and Strauss 1967). This process involved identifying a theme and then attempting to verify, confirm and qualify it by searching through the data. Once all the data matching that theme was located, the process was repeated until each theme present in the data was identified. Four members of the research team individually attempted the process of theme identification identified above before collation by the principal investigator into the thematic categories that are presented in section 4.

9.2.7 Dissemination of results

The research team agreed with the NHC to hold a general meeting for all participants, family and members of the wider Pacific community at the conclusion of the study. The challenge in disseminating information in the Pacific community is that the modes of communication are unique to each ethnicity. It was decided that depending on interest following the general meeting an opportunity for smaller ethnic-specific feedback to the participants and their families, providing information to them in their languages and in a culturally safe environment and manner that is suitable to them, would be offered.

9.2.8 Ethics approval

The research project was given ethics approval by the Northern X Regional Ethics Committee following revision of some aspects of the study and study consent and information forms. Approval was given on 23 October 2008 until 11 May 2009. (Reference number NTX/08/09/087.)

9.3 Methodological limitations

9.3.1 Pacific diversity

The use of the umbrella term ‘Pacific Islander’ coined for political and utility purposes some 30-40 years ago is a fundamental methodological limitation in this study. Historically in the 1970s and 1980s a ‘Pacific person’ or ‘Pacific Islander’ commonly denoted Pacific peoples from the four largest population groups residing in New Zealand: respectively Samoan, Cook Islands Māori, Tongan and the Niuean island groups. The term Pacific or Pacific Islander now includes (in 2008) Fijian, Tokelauan, Tuvaluan, and people from Kiribati, Papua New Guinea, the Solomon Islands and French Polynesia (eg, Tahiti), to name but a few of the groups now covered by the term.

There is an ever-expanding number of ethnically disparate and diverse groups (which also includes Pacific peoples of mixed ancestry, including multiple Pacific cultures as well as Pacific/non-Pacific backgrounds) represented by the umbrella terms Pacific, Pasefika, Pacific Islander or Polynesian (Ministry of Health 2008a), creating a situation whereby the homogeneity suggested by the umbrella terms is difficult to continue to justify and even perhaps significantly misleading considering the wide range of languages, heritages, national origins, and ethnic affiliations so encompassed. The single most important limitation of this study is the treatment of the diverse participants as if they were a homogenous group. The scientific method rightly holds that as long as the limitations are openly acknowledged, the impact of the identified limitation on the validity of the results can be taken into account and addressed meaningfully. It is important to note here however that the majority of participants in this study were drawn from the larger ‘traditional’ Pacific groups, namely Samoan, Cook Islands Māori, Tongan and Niuean groups. The age demographic of the participants also meant greater homogeneity than if New Zealand-born Pacific peoples were also a focus of the research.

9.3.2 Interview deficiencies

Facilitation of focus groups that allows each participant to contribute freely and openly is a complex task. The dynamic set-up in a focus group may mean that people say they agree with others even when they do not, and do not open up completely for fear of being seen to have attitudes and feelings that would not be received favourably by others. In comparing the data from the focus groups and the individual interviews, a very strong conflict between the individual interviews and the focus groups emerged. The sense of shame and embarrassment the elderly Pacific caregivers had surrounding having a grandchild with a chronic illness – and particularly some forms of disability – was very strong in the individual interviews. These feelings were absent or spoken of in a diluted manner in the focus groups. This illustrates the common problem in qualitative research of people expressing an opinion that is contrary to their true attitude or feeling regarding the matter under discussion (Silverman 1994; Heritage 1984). Combating this often-found problem is difficult if only one method of interviewing is undertaken. In the example above, if individual interviews had not been conducted the significant feelings of shame would not have been discovered.

The major difficulty with both focus group and individual interviews is that the facilitator can lead the discussion to such an extent that preconceived notions of what participants 'should' experience biases the integrity of the study data (Chui and Knight 1999). Avoiding a certain degree of facilitator bias is almost impossible. The best that can be done is for the facilitator to be well trained and for other forms of information gathering to take place, as in this study which used two forms of data gathering – focus groups and individual interviews. Finally, a method known as analysing for deviant or negative cases in which themes or emerging propositions that run counter to the majority of observed data should be present. That is, there should not be total agreement between all participants. Fortunately there was a sufficient range of views to indicate that there was not an exaggerated facilitator or interviewer bias.

9.3.3 Resource limitations

Qualitative cross-cultural research projects are expensive. Non-English speaking participants not only add cultural complexity but require native speaking facilitators who are well-trained to run focus groups and translators for individual interviews. The large amount of transcription material capturing all the spoken information requires translation. With each additional ethnic group added to the research design significant cost is added. There is therefore a limit to the number of focus groups and individual interviews that can be conducted. Overall 24 participants took part, with 20 meeting the criteria for inclusion in the final analysis. It became apparent that the common themes reached saturation point and by the completion of the interviews the information being conveyed by the participants took on a familiar feel. This indirectly indicates that additional interviews may not have yielded any further significant information, although this is a research assumption.

9.3.4 Self-selection bias

It is likely that the type of elderly caregivers who would agree to participate in this type of qualitative study would be more optimistic and positive about living with a child or young person with a chronic illness or disability than those who were ashamed or excessively burdened by their situation. Those caregivers would be more likely to have negatively stereotypical views of chronic illness or disability and hold more negative views or traditional beliefs and so be less likely to participate in this type of study. They might want to hide not only their negative attitudes but also, as often is the case amongst people from small communities, to hide their personal circumstances from other members of their cultural group.

The impact of self-selection bias on any research project, both qualitative and quantitative, is it tends to make results look more positive. In regard to this study the analytical direction that the results take would be an impression of elderly Pacific caregivers' attitudes, values and practices that would be artificially more optimistic and positive.

9.3.5 Research validity

At the outset of this research project certain principles guided the conceptualisation of the design and implementation of the study. These principles are contained within the Health Research Council (HRC) of New Zealand's *Strategic Plan for Pacific Research* (HRC 2006). When proposals are submitted to the HRC's annual contestable funding round, they are assessed for relevance to the research portfolio priorities and against the criteria developed by each expert panel to identify the research of highest priority to their respective populations. The criteria for Pacific health research involve classifying research as: Pacific Relevance; Pacific Partnership; or Pacific Governance.

Pacific Relevance is research that focuses on an issue of importance to Pacific peoples, such as the predicament of elderly Pacific caregivers and vulnerable Pacific children or young people in their care, and involves Pacific peoples through consultation, participation and dissemination of findings. The strategy goes on to assess whether a sufficient number of Pacific peoples are included as participants in the research for the findings to contribute to the body of knowledge on Pacific health. The research should also provide a training opportunity for a Pacific researcher. This research project meets all of these requirements particularly as two of the research team are adult students steeped in their culture and attempting to develop research skills. It is important to note that the HRC not only prioritises Pacific research but also research on children and youth, older adults, and people with disability. On these grounds this research project clearly had a strong mandate for being undertaken as it fully met HRC guidelines. More importantly, the research team paid close attention to ensuring appropriate consultation and care of participants. Careful consideration of the dissemination process was part of the planning for the project, which also met criteria for Pacific Partnership and Governance as Pacific peoples were involved in the overall design and governance of the project.

Scientific robustness requires the study design to meet acceptable academic standards and the project was fortunate to have supervision and oversight provided by Dr Nosa, an experienced and highly regarded Pacific expert in qualitative research methods. The main

shortcoming in the study design was the failure to ensure that all interviews were conducted in the native language of the participants. The focus group and two of the three interviews conducted in English lacked the depth of feeling communicated in interviews conducted in first language. All interviews should, ideally, have been analysed in first language to avoid loss of nuance. Despite these limitations, it is the opinion of the research team that the main challenges faced by elderly Pacific peoples in regard to caregiving have been identified.

9.4 Study design forms

9.4.1 Data collection form

QUALITATIVE STUDY OF INFORMAL PACIFIC ELDERLY CAREGIVERS OF A CHILD OR YOUNG PERSON WITH A CHRONIC ILLNESS OR DISABILITY

Date of Focus Group • •

Personal Information

First Name

Surname

Ethnicity

How old is the child or young person you care for?

0-2 years	<input type="text"/>	12-14 years	<input type="text"/>
3-5 years	<input type="text"/>	15-17 years	<input type="text"/>
6-8 years	<input type="text"/>	18 years +	<input type="text"/>
9-11 years			<input type="text"/>

What is the Nature of the child or young persons Chronic Illness or Disability

Physical - please specify

Sensory - please specify

Intellectual - please specify

How long have you cared for them? Years

What was the cause of their illness or disability?

Place of Residence – Where does the child live most of

Own Home Residential Renting Alone Renting with others
Living with parents or siblings Living with other relatives

Service Information

How long has the child been receiving services if any?

Less than 6 months	<input type="text"/>	1-5 years	<input type="text"/>
6-12 months	<input type="text"/>	5-10 years	<input type="text"/>
Other (specify) _____	<input type="text"/>	More than 10 years	<input type="text"/>

9.4.2 Participant information sheet

QUALITATIVE STUDY OF INFORMAL PACIFIC ELDERLY CAREGIVERS OF A CHILD OR YOUNG PERSON WITH A CHRONIC ILLNESS OR DISABILITY

Kia Orana, Fakalofa lahi atu, Ni Sa bula Vinaka, Talofa lava, Malo e lelei.

You are invited to participate in this research effort to understand the needs of elderly Pacific people who are the primary care-givers for Pacific children or young people who live with chronic illness or disability. We are a team of Pacific researchers from Vaka Tautua Ltd a company owned by Pacific Information Advocacy Support Services also known as PIASS Trust. We have been contracted to undertake this piece of research by the National Health Committee. The lead researcher for the project is Dr Siale Alo Foliaki who is the father of a child with Spina Bifida. Dr Foliaki is passionate about quality care for Pacific children who have chronic illnesses or disabilities and has extensive research experience among Pacific people in New Zealand in both disability and mental health areas.

The major goals of this research project is:

- To obtain information that will contribute to how the government might respond to the needs of Pacific elderly people caring for a child or young person with a disability.
- To identify the needs of elderly Pacific caregivers and their families to determine the appropriateness of existing support services and community based agencies supporting them to care for their chronically ill or disabled child or young person.
- To identify areas of improvement and requirements for development of health and disability support services to support elderly Pacific care givers caring for children and young people with a chronic illness or disability.

The collection of information will be conducted through individual interviews and focus groups where you will be joined by other elderly Pacific people caring for a child or young person with a chronic illness or disability in their families and from your own community. Members of the research team will work with you to either organise an interview or organize an appropriate time for the focus group. A copy of the interview questions will be made available to you and with your consent the focus groups will be taped, scribed and later transcribed into English by the researchers. A copy of the focus group transcript will be made available to you and other participants to check on the accuracy of the information collected. Please note that participants in the focus groups will be unable to withdraw their contributions to the focus groups should they decide to withdraw from the study.

Possible participants for this research must be an elderly Pacific person (defined as 60 years of age and above) who is the primary unpaid caregiver of a child of young (under the age of 18) Pacific person who has a chronic illness or disability. However, any caregiver suffering any significant medical, psychiatric or alcohol and drug related disorder will not be eligible to participate in this study.

Here are some examples of the types of questions you will be asked if you agree to participate in the study:

Can you describe your current residence and how this impacts on your ability to look after the child or young person with a chronic illness or disability you care for?

Are there any problems with your current place of residence that affects the quality of care you can provide to the child or young person with a chronic illness or disability?

In an ideal world what type of home would best suit you and the needs of the child or young person with a chronic illness or disability you care for?

Ethics and Confidentiality

No material which could personally identify you will be used in any reports of findings about this study. The records will be kept in a locked file throughout the study in order to ensure your confidentiality. Only the project team will have access to the completed questionnaires and transcripts of the focus groups. On completion of the study, the transcripts will be kept by the Ministry of Health for ten years as required by research protocols in New Zealand.

“If you have any queries or concerns regarding your rights as a participant in this research study, you can contact an independent Health and Disability Advocate. This is a free service provided under the Health & Disability Commissioner Act.

Telephone (NZ wide):	0800 555 050
Free Fax (NZ wide):	0800 2787 7676 (0800 2 SUPPORT)
Email:	advocacy@hdc.org.nz

The information collected will be used to prepare a report to the National Health Committee by the end of May 2009.

It is also important to note that if the Principal Investigator has significant concerns about your safety or others confidentiality may be broken as required by law or applicable codes of practice.

After the completion of the report, the researchers will return to you to provide feed back on the main findings of this study.

Statement of Approval

This study has received ethical approval from the Northern X Regional Ethics Committee.

If you have any other questions or would like to receive more information about this research project, please contact Dr Siale Alo Foliaki, Principal Investigator at Vaka Tautua.

Wella Building, Level 3, 15 Sultan Street, Ellerslie, Auckland

Phone (09) 589 1922

Email: saej@ihug.co.nz

9.4.3 Consent form

QUALITATIVE STUDY OF INFORMAL PACIFIC ELDERLY CAREGIVERS OF A CHILD OR YOUNG PERSON WITH A CHRONIC ILLNESS OR DISABILITY

Principle Investigator: Dr Siale Alo Foliaki

I have read and I understand the information sheet dated 15th October 2008.

I have been given enough information in my own language to fully understand the nature and goals of this research project.

I have had an opportunity to ask questions and have them answered.

I understand the information given by the research team and have been given the opportunity to seek further clarification or explanations.

I understand that I may withdraw myself and /or any information I have provided for this project at any time before the final analysis phase without having to provide reasons and that if I withdraw from the project, any data I have supplied will be returned to me or destroyed. If however my contributions have been made during a focus group then I understand these contributions will not be able to be withdrawn.

I understand that the information I provide will be treated confidentially and accessible only to the researchers and reported only in summative form. I also understand that information will be used for the purpose of only this research. I am aware that if the Principal Investigator has significant concerns about the safety of myself or to others confidentiality may be broken as required by law or applicable codes of practice.

I am also aware that the research team may want to publish my particular experience as a case study to illustrate important challenges facing informal Pacific elderly caregivers caring for a child or young person with a chronic illness or disability. In this case I understand that the research team will come back to me and show me what they would like to publish into the public domain. I will have a chance to either agree or disagree with publication of my experience at that time.

I consent to an interpreter if necessary.

REQUEST FOR INTERPRETER

English	I wish to have an interpreter.	Yes	No
Māori	E hiahia ana ahau ki tetahi kaiwhakaMāori/kaiwhaka pakeha korero.	Ae	Kare
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	Io	Sega
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai
Samoan	Ou te mana’o ia i ai se fa’amatala upu.	Ioe	Leai
Tokelauan	Ko au e fofou ki he tino ke fakaliliu te gagana	Ioe	Leai

	Peletania ki na gagana o na motu o te Pahefika		
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai

I agree to take part in this research []

I agree to be audio taped []

I do not agree to be audio taped []

NAME.....

SIGNED.....

DATE.....

Vaka Tautua Version IV

15/10/08

QUALITATIVE STUDY OF INFORMAL PACIFIC ELDERLY CAREGIVERS OF A CHILD OR YOUNG PERSON WITH A CHRONIC ILLNESS OR DISABILITY

Residence

Can you describe your current residence and how this impacts on your ability to look after the child or young person with a chronic illness or disability you care for?

Are there any problems with your current place of residence that affects the quality of care you can provide to the child or young person with a chronic illness or disability?

In an ideal world what type of home would best suit you and the needs of the child or young person with a chronic illness or disability you care for?

Impact of Disability on your life and family

How has caring for your chronically ill or disabled family member affected your life?

How has caring for your ill or disabled family member affected your wider family life?

How has the situation affected you emotionally?

How has the situation affected you financially?

What other ways has caring for the child or young person with a chronic illness or disability impacted on you and your family?

Support Services

What support services do you access on behalf of your family member with a chronic illness or disability?

What type of support do you receive?

How effective was the support you received?

Do you know of any other support services you are entitled to access in relation to caring for your child or young person?

How do you know what services you are entitled to?

What suggestions do you have to improve the services that you receive?

What needs do you have that are not being met by the services you currently receive?

Medical Care

Can you tell us about what medical problems the member of your family that you help care has?

What more do you think you should know about your family members chronic illness or disability?

How do you access medical help for your family member with an illness or disability.

Development of Service Providers

What are your thoughts on the services available that support you and your family member with a chronic illness or disability?

What additional services would you like to see made available for a child or young person with a chronic illness or disability and their families?

Are the services culturally appropriate?

How can service providers make their services more culturally appropriate for you and your family?

How did you find out about Disability Support Services, was it through your family doctor or other means?

Which would be the most appropriate way for learning about health providers or disability support services?

Vaka Tautua Version II 23/09/08

For back cover:

REDESIGN

I've been designed to be easy to read and download in electronic form as well. See www.nhc.health.govt.nz.

REDUCE

We always aim to reduce our own resource use.

I'm made of 100 percent fibre from sustainable well-managed forests.

RECYCLE

I'm also 100 percent recyclable.

REUSE

Don't need to keep a copy? Feel free to share me around or return me to the NHC and they'll pass me on to someone else.