# AN INTERVENTION TRIAL FOR MÅORI AT RISK OF DIABETES-RELATED LOWER LIMB PATHOLOGY

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# TABLE OF CONTENTS

TABLE OF CONTENTS	2
LIST OF TABLES	
TABLE OF FIGURES	
ACKNOWLEDGEMENTS	
RESEARCH OUTCOMES	10
Reports	10
Conference papers delivered	
Seminars and Presentations	
Funding applications	
Summary of discoveries, achievements and Reccomendations	
Summary of contribution to undersanding of Māori diabetes related foot care	
EXECUTIVE SUMMARY	
Aims	12
Research Process	
Key Quantitative Findings	13
Qualitative findings	
Stigma	14
Unhelpful contexts	14
Lack of information and understanding	14
Unhelpful structural processes	
In Summary	
Barriers to good Maori toot care	
Implement Health Care practices that Are Relevant And Responsive to Maon	
Implement enabling, focused education and information programmes	15
Redesign health systems	
Enablers to good Māori foot care	
In Summary	
Reccomendations Of this research	16
Apply Māori values, Beliefs and practices in Māori foot care	
Create helpful contexts	
Healthcare services	
Provide enabling education programmes and Healthcare Workforce	
Health professional education and Recruitment	/۱ ۱۵
Research	10
Conclusion	10
CHAPTER ONE INTRODUCTION	
Terms	
Overview of report	20
Background: Summary literature review	21
CHAPTER TWO RESEARCH PROCESS	

Aims	23
Objectives	23
Hypotheses	24
Study Design	24
Advisory Group	24
Theoretical Framework	25
Ethics	26
Informative Phase	27
Recruitment	
Recruitment of Key Informants	27
Recruitment of Focus Groups	27
Data Collection Process	
Key Informant interviews	28
Focus Groups	28
Survey development	
final Qualitative data analysis	
Non-Māori data Analysis	29
Intervention Phase	29
Settings	
'Usual Care' Setting	30
Intervention setting	
Enhanced podiatry care for intervention group	30
Risk categories	31
Podiatry audit	
Education Wananga for Intervention group	
Selection Criteria	
Recruitment of 'Usual Care' and 'Intervention' groups	
Survey	
Baseline information	
tollow-up Information	
Data Collection Process	
Quantitative data analysis	
Summary of research processes	34
CHAPTER THREE QUALITATIVE FINDINGS: BARRIERS TO MĀORI FOOT CARE	35
Introduction	35
Stigma	35
External stigma: Health professional talk	
Trivialising Māori questions	
Stigma within the health care system	
Internalised stigma	
Unhelpful contexts	39
Belief contexts	40
Personal contexts	
Unhelpful thinking processes	40
Lack of acceptance of the diagnosis of diabetes	41
Fear of the diagnosis	42

Health Care Practices That Are Relevant And Responsive To Māori         Celebrate connection         Ensure culturally RESPONSIVE healthcare providers <b>Create helpful contexts</b> new ways of thinking: self engagement         Whānau and community engagement         Establish clinical connections <b>Provide enabling, focused education programmes</b> Crucial information: "What I want to know is the facts!"         Ensure Māori and age relevant content         Use Locally appropriate and relevant approaches         Multiple information sources         Appropriate venues and times <b>Redesign structural processes</b> Preventive philosophy of health care         The whole package         Coordinated and integrated services         AAA – Available, accessible, affordable         Sustainable funding         Quality assurance         Media         APPLY Creative thinking	<b>58</b> 60 60 60 62 63 63 64 64 67 67 67 67 68 70 70 71 73 73 73 74 74 75 75 75 76 76 77 77 77 77 78 79
Health Care Practices That Are Relevant And Responsive To Māori         Celebrate connection         Ensure culturally RESPONSIVE healthcare providers <b>Create helpful contexts</b> new ways of thinking: self engagement         Whānau and community engagement         Establish clinical connections <b>Provide enabling, focused education programmes</b> Crucial information: "What I want to know is the facts!"         Ensure Māori and age relevant content         Use Locally appropriate and relevant approaches         Multiple information sources         Appropriate venues and times         Preventive philosophy of health care         The whole package         Coordinated and integrated services         AAA – Available, accessible, affordable         Sustainable funding         Quality assurance         Media	58 60 60 60 62 63 63 64 67 67 67 67 68 70 70 70 70 70 70 70 71 73 73 74 74 74 75 75 75 75 75 75 77 77
Health Care Practices That Are Relevant And Responsive To Māori         Celebrate connection.         Ensure culturally RESPONSIVE healthcare providers. <b>Create helpful contexts</b> new ways of thinking: self engagement         Whānau and community engagement         Establish clinical connections <b>Provide enabling, focused education programmes</b> Crucial information: "What I want to know is the facts!"         Ensure Māori and age relevant content         Use Locally appropriate and relevant approaches         Multiple information sources         Appropriate venues and times         Preventive philosophy of health care         The whole package         Coordinated and integrated services         AAA – Available, accessible, affordable         Sustainable funding.         Ouality assurance	<b>58</b>
Health Care Practices That Are Relevant And Responsive To Māori         Celebrate connection.         Ensure culturally RESPONSIVE healthcare providers. <b>Create helpful contexts</b> new ways of thinking: self engagement         Whānau and community engagement         Establish clinical connections <b>Provide enabling, focused education programmes</b> Crucial information: "What I want to know is the facts!"         Ensure Māori and age relevant content         Use Locally appropriate and relevant approaches         Multiple information sources         Appropriate venues and times <b>Redesign structural processes</b> Preventive philosophy of health care         The whole package         Coordinated and integrated services         AAA – Available, accessible, affordable         Sustainable funding	58 60 60 62 63 64 64 67 67 67 67 70 70 70 70 70 70 70 70 70 71 73 73 74 74 75 75 75
Health Care Practices That Are Relevant And Responsive To Māori         Celebrate connection         Ensure culturally RESPONSIVE healthcare providers <b>Create helpful contexts</b> new ways of thinking: self engagement         Whānau and community engagement         Establish clinical connections <b>Provide enabling, focused education programmes</b> Crucial information: "What I want to know is the facts!"         Ensure Māori and age relevant content         Use Locally appropriate and relevant approaches         Multiple information sources         Appropriate venues and times <b>Redesign structural processes</b> Preventive philosophy of health care         The whole package         Coordinated and integrated services	58 60 60 62 63 63 64 67 67 67 67 67 67 67 70 70 70 70 70 70 70 71 73 73 74 74
Health Care Practices That Are Relevant And Responsive To Māori         Celebrate connection         Ensure culturally RESPONSIVE healthcare providers <b>Create helpful contexts</b> new ways of thinking: self engagement         Whānau and community engagement         Establish clinical connections <b>Provide enabling, focused education programmes</b> Crucial information: "What I want to know is the facts!"         Ensure Māori and age relevant content         Use Locally appropriate and relevant approaches         Multiple information sources         Appropriate venues and times         Preventive philosophy of health care         The whole package	58 60 60 62 63 64 67 67 67 67 67 70 70 70 71 73 74 74 75
Health Care Practices That Are Relevant And Responsive To Māori         Celebrate connection         Ensure culturally RESPONSIVE healthcare providers <b>Create helpful contexts</b> new ways of thinking: self engagement         Whānau and community engagement         Establish clinical connections <b>Provide enabling, focused education programmes</b> Crucial information: "What I want to know is the facts!"         Ensure Māori and age relevant content         Use Locally appropriate and relevant approaches         Multiple information sources         Appropriate venues and times <b>Redesign structural processes</b> Preventive philosophy of health care	58 60 60 62 63 64 64 67 67 67 67 67 67 70 70 70 70 70 70 70 71 73 73 74
Health Care Practices That Are Relevant And Responsive To Māori         Celebrate connection.         Ensure culturally RESPONSIVE healthcare providers. <b>Create helpful contexts</b> new ways of thinking: self engagement         Whānau and community engagement         Establish clinical connections <b>Provide enabling, focused education programmes</b> Crucial information: "What I want to know is the facts!"         Ensure Māori and age relevant content         Use Locally appropriate and relevant approaches         Multiple information sources         Appropriate venues and times	58 60 60 62 63 63 64 67 67 67 67 68 70 70 70 70 71 73 74
Health Care Practices That Are Relevant And Responsive To Māori         Celebrate connection.         Ensure culturally RESPONSIVE healthcare providers. <b>Create helpful contexts</b> new ways of thinking: self engagement         Whānau and community engagement         Establish clinical connections <b>Provide enabling, focused education programmes</b> Crucial information: "What I want to know is the facts!"         Ensure Māori and age relevant content         Use Locally appropriate and relevant approaches         Multiple information sources         Appropriate venues and times	58 60 60 62 63 63 64 67 67 67 67 67 67 70 70 70 70 71
Health Care Practices That Are Relevant And Responsive To Māori         Celebrate connection         Ensure culturally RESPONSIVE healthcare providers <b>Create helpful contexts</b> new ways of thinking: self engagement         Whānau and community engagement         Establish clinical connections <b>Provide enabling, focused education programmes</b> Crucial information: "What I want to know is the facts!"         Ensure Māori and age relevant content         Use Locally appropriate and relevant approaches         Multiple information sources	58 60 60 62 63 64 64 67 67 67 67 67 70 70 70
Health Care Practices That Are Relevant And Responsive To Māori         Celebrate connection.         Ensure culturally RESPONSIVE healthcare providers. <b>Create helpful contexts</b> new ways of thinking: self engagement         Whānau and community engagement         Establish clinical connections <b>Provide enabling, focused education programmes</b> Crucial information: "What I want to know is the facts!"         Ensure Māori and age relevant content         Use Locally appropriate and relevant approaches	58 60 60 62 63 63 64 67 67 67 68 70 70
Health Care Practices That Are Relevant And Responsive To Māori         Celebrate connection.         Ensure culturally RESPONSIVE healthcare providers.         Create helpful contexts         new ways of thinking: self engagement         Whānau and community engagement         Establish clinical connections         Provide enabling, focused education programmes         Crucial information: "What I want to know is the facts!".         Ensure Māori and age relevant content	58 60 60 62 63 63 64 67 67 67 67 67 70
Health Care Practices That Are Relevant And Responsive To Māori         Celebrate connection         Ensure culturally RESPONSIVE healthcare providers         Create helpful contexts         new ways of thinking: self engagement         Whānau and community engagement         Establish clinical connections         Provide enabling, focused education programmes         Crucial information: "What I want to know is the facts!"	58 60 60 62 63 64 64 67 67 67 68
Health Care Practices That Are Relevant And Responsive To Māori         Celebrate connection.         Ensure culturally RESPONSIVE healthcare providers.         Create helpful contexts         new ways of thinking: self engagement         Whānau and community engagement         Establish clinical connections	58 60 60 60 60 62 63 63 64 64 67
Health Care Practices That Are Relevant And Responsive To Māori         Celebrate connection         Ensure culturally RESPONSIVE healthcare providers         Create helpful contexts         new ways of thinking: self engagement         Whānau and community engagement         Erstehlich elipical contexts	58 60 60 60 62 63 64
Health Care Practices That Are Relevant And Responsive To Māori         Celebrate connection         Ensure culturally RESPONSIVE healthcare providers	
Health Care Practices That Are Relevant And Responsive To Māori       Celebrate connection         Celebrate connection       Ensure culturally RESPONSIVE healthcare providers         Create helpful contexts       Celebrate contexts	
Health Care Practices That Are Relevant And Responsive To Māori Celebrate connection Ensure culturally RESPONSIVE healthcare providers	
Health Care Practices That Are Relevant And Responsive To Māori	<b>58</b> 60
Health Care Practices That Are Relevant And Responsive To Māori	58
Introduction	58
THAPTER FOUR: ENABLERS TO MAORI FOOT CARE	
Summary of Barriers to Māori foot care	
Intrituouilly	
LOSIS OF GOOD TOOT CARE	
Lack of sustainable funding	
Lack of Maori practitioners	
Philosophy of health care – lack of preventive resources	
Limited menu	
Age inappropriate	49 50
Outurally Inappropriate Lacking credibility to Māori	48 ۸۵
Lack of information and understanding	
Clinical contexts	40
Work contaxts	
Community contexis	
vvnanau nistories Community contexts	
Whānau jokes Whānau histories Community contexts	۲ <del>۱</del>
Prioritising whānau Whānau jokes Whānau histories Community contexts	44
Lack of whānau support Prioritising whānau Whānau jokes Whānau histories Community contexts	44 44
Unhelpful Whānau contexts Lack of whānau support Prioritising whānau Whānau jokes Whānau histories Community contexts	

CHAPTER FIVE: QUANTITATIVE FINDINGS	80
Recruitment and Follow-Up	80
Participant Characteristics	
Intervention Characteristics	00
Intervention Impact	
Discussion	
CHAPTER SIX: INTERVENTION PARTICIPANT FEEDBACK	
Lanolin emollient foot cream	
Silver colloidal merino wool socks	
Referral to other clinicians	
Provision of information at podiatry clinics	
Profile Education wānanga	100
Education Wānanga weekend evaluation	100
Summary	102
CHAPTER SEVEN: DISCUSSION of WHAT WORKS BEST TO REDUCE THE IM	PACT OF
DIABETES-RELATED FOOT DISEASE FOR MĀORI?	103
Did this research achieve its aims and objectives?	
Summary of Quantitative findings	104
Summary of Qualitative findings	104
Stioma	105
Barriers to good Māori foot care	
Unhelpful contexts	
Lack of information and understanding	106
Unhelpful structural processes	106
In Summary	107
Implement Health Care practices that Are Relevant And Responsive to Māori	108
Enablers to good Māori foot care	
Create neiptul contexts	108
Redesign health systems	
In Summary	
Limitations of this research	
Passamendations Of this reasonab	111
Apply Maori values, Bellets and practices in Maori foot care	
Culture	111
Whānau and community Engagement	
Ensure Mindful self engagement	
Healthcare services	112
Redesign structural processes	112
Increase clinical connection with Māori who need foot care	113
Establish coordinated and integrated services	113
Evaluation of services and education programmes	
Media	113 111
Provide enabling education programmes and Healthcare Workforce	

Health professional education and Recruitment	
Enable meaningful patient education and wananga	
Conclusion	116
Glossaries	
Glossary of Maori terms	
LIST OF ABBREVIATIONS	
APPENDICES	
Appendix One: Literature Review: Waewae Tapu: The sacred foot (B Waiora 2007)	rown and Taupua
Appendix Two: information and Consent forms Participant Information Sheet Approval form: Auckland University of Technology Ethics committee (AUTEC) Participant consent form	<b>142</b> 
Appendix Three: interview schedules Focus Group Interview Schedule Interview schedule for key informant interviews	<b>146</b> 
Appendix Four: Summary of baseline and 12 month follow-up survey assessment	and podiatry foot 148
Appendix Five: Question 6	150
Appendix Six: Justification and operational definition of podiatric interven	ition151
Appendix Seven Lifesock	155
REFERENCES	

# LIST OF TABLES

Table 1 Number of Participants at Baseline and one year follow-up	. 80
Table 2. Comparison of key basic measures for lost to followup	. 81
Table 3. Demographics of Participants	. 81
Table 4. Utilisation of health Services	82
Table 5. Diabetes History	. 84
Table 6. Health status of participants	85
Table 7. Lower limb status of participants	85
Table 8. Participant health behaviours	86
Table 9. Baseline podiatry assessment of participants	87
Table 10. ankle-brachial index	88
Table 11. Baseline Musculoskeletal Assessment	. 89
Table 12. Baseline podiatry assessment of participants	90
Table 13 Referral to other Services	91
Table 14 Unadjusted Mean Scores	.92
Table 15 GEE Repeated Measeures Model	. 92
Table 16. Repeated Measures Logistic Model	93

# TABLE OF FIGURES

Figure 1 Theoretical framework. A Māori inquiry paradigm: a health research perspective	
(Ratima 2003)	25

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Despite the above comprehensive list of contributors, many individuals have been involved in this project throughout its progression. The research team would like to extend a sincere apology to any person left accidentally and unknowingly from the list. Please be assured that any omission was not intentional.

This project was reviewed and accepted by the Northern Y Ethics Committee (Approval No NTY/05/08/055) and the Auckland University of Technology Ethics Committee (AUTEC) (Approval No 07/198).

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## RESEARCH OUTCOMES

### REPORTS

Final report to the HRC January 2010 Browne, J., Garrett, N. 'Feet for Life: An intervention trial for Māori at risk of diabetes-related lower limb pathology', Taupua Waiora AUT University

## CONFERENCE PAPERS DELIVERED

- Browne J, Ruakere T, Garrett N, Ruakere H, Ihaka B, Armstrong J, Ferguson L, Rome K. 2009 Rhetoric or reality? Are service delivery and health policy supporting preventive contexts for Māori diabetes-related foot care? Health Services Policy Research Conference, Brisbane Exhibition and Convention Centre Nov 2009 Brisbane Australia.
- Ihaka B, Rome K, Bayley A, Browne J, H Ruakere, T Ruakere, N Garrett Implementation of a Podiatric Screening Tool for Diabetes-Related Foot Complications Among Māori. Poster. New Zealand Society for the Study of Diabetes conference (NZSSP) Christchurch April 2009.
- Ihaka, B. Bayley, A., Rome, K., Ferguson, L., Garrett, N., Poratt, D., McNeill, E., Marsden, L., Rapana, S., Penney, L. Development and implementation of an evidence-based podiatric screening tool for diabetes-related foot complications among Maori. New Zealand Podiatry Conference. Christchurch, 2008

#### SEMINARS AND PRESENTATIONS

- Ferguson, L., Armstrong, J., Ruakere, H., Ruakere, T., Browne, J., 2008 Taupua Waiora Complexities of Māori research: Are we researchers or master jugglers? Nov 2008 presented to Faculty of Health AUT
- Browne, J., Ruakere T. 2009 Podiatry Research Away Day November 'Creating helpful contexts for Māori diabetes-related foot care'
- Ihaka, B. 2009 Podiatry Research Away Day, November 'Heel the world'

## FUNDING APPLICATIONS

A funding application for future research on the concept of Whānau Engagement in Foot Health was successfully submitted to the HRC with Te Tihi Hauora o Taranaki PHO. The HRC funded this study through Te Tihi Hauora o Taranaki PHO. Successfully funded but later withdrawn.

## SUMMARY OF DISCOVERIES, ACHIEVEMENTS AND RECCOMENDATIONS

- The need to change policy directions toward an increased and more genuine emphasis on prevention of limb pathology? through the availability and funding of preventive health resources that go beyond education programmes
- The urgent need for all health professionals to put training in cultural responsiveness within the clinical context into practice, in order to increase the capacity of health workers to improve client health status
- The importance of genuinely understanding Māori perspectives of health promotion interventions such as the importance of relationships and kanohi ki te kanohi (face to face) connections when working with Māori; of whānau involvement, and how to conduct effective education and foot care service for Māori
- The urgent need for funding of programmes to support whānau and community involvement in diabetes related foot care that goes beyond the attendance in the clinic of a partner or whānau member.
- The need for standardization of podiatry assessments and tailoring interventions to the individual.
- The retention of diabetes knowledge through regular contact with health providers who provide education as part of their service

## SUMMARY OF CONTRIBUTION TO UNDERSANDING OF MAORI DIABETES RELATED FOOT CARE

- Improved understanding of Māori perspectives of the barriers and enablers to Māori foot health and care.
- Identification of the perspectives of Māori living with diabetes and Māori health professionals about "what works best for Māori to reduce the impact of diabetic foot disease".
- Improved understanding of diabetes related foot health among Māori
- Improved understanding of how context creates meaning, and that no one size fits all
- Potential to explore traditional methods of foot care and how to use both traditional and modern methods effectively Explore ways in which whānau, allied and alternative practitioners can best contribute to foot care
- Need for research into how workplaces can better support foot injury prevention
- Need for education programmes for both Māori and health care workers focused on foot care to enable them to know how to care for their feet The importance of health promotion to ensure patients retain knowledge that assists them to maintain the health and wellbeing of themselves and their whānau

# EXECUTIVE SUMMARY

# They just do it and they just go along with it and I say, "What did you pick up with those machines on my feet?", and they say I'm fine! I'm not fine or I'd be dancing out of here!!

### (Focus Group Participant)

This research project on improving diabetes related lower limb outcomes for Māori has brought together members of the Māori community, a range of health professionals, professional bodies such as District Health Boards, academics, researchers and administrators to achieve a common goal.

## AIMS

The purpose of the project was to improve lower limb outcomes for Māori who live with diabetes. In order to achieve this overall goal, the aims were:

- Develop, implement and evaluate a lower limb intervention for Māori with diabetes, consistent with the aspirations of, and acceptable to Māori.
- Create new knowledge to inform policy, funding decisions, and health service delivery
- Provide a foundation for further research

# RESEARCH PROCESS

The research involved a multi-method process based on a Māori theoretical approach. The research design was a community trial of a foot care intervention. The proposed project had informative and intervention phases as briefly defined below:

#### **Informative Phase**

Key informant interviews (20) and focus groups (3 groups of 9 participants) were conducted with people diagnosed with diabetes and identified as having diabetes related foot pathology. The initial findings from the interviews and focus groups along with a review of the diabetes literature informed the development of a podiatry intervention for Māori and assessment tools utilized in the intervention phase. At the completion of the projection this data was then reviewed for qualitative information. The qualitative data were entered and managed in NVivo and analysed using thematic analysis.

#### **Intervention Phase**

A year-long trial intervention for Māori with diabetes was developed and implemented. The intervention involved each participant being clinically assessed using an enhanced version of the Wellington Independent Practice Association (WIPA) podiatric tool, and an individual health plan being developed dependent on participants' needs. This included podiatric treatment and education; provision of skin emollients, hosiery, and advice on footwear; facilitated co-ordination of access to other health professionals and social services; appointment reminder calls and provision of transport or home visits; and invitation to a diabetes self-management wānanga.

For practical purposes of delivering the podiatric intervention, there were four clinic settings for this research, two control group (usual care) clinic settings and two intervention clinic settings.

Interviews and foot assessments were conducted with at baseline (before intervention) and 12 months later for both the intervention control ('usual care') groups. The questionnaire included questions on demographics, diabetes history, health service utilisation, diabetes knowledge, health status, health behaviors, and podiatry measures. A few questions on process and outcome evaluation of the intervention were included at 12 month follow-up and qualitatively analysed along with the informative phase data.

A total of 125 Māori participants were recruited to the intervention study; 60 in the intervention and 65 in control group. The final sample number at the end of the study was 97; 50 in the intervention and 47 in the control group. Final dropout rates of 17% and 28% respectively are close to those estimated in the planning stages of this research.

Models to examine the effect of the intervention trial on key outcome measures were analysis using repeated measures ANOVA/Logistic regression models. The models were adjusted for age, sex and years since diagnosis of diabetes.

# KEY QUANTITATIVE FINDINGS

- Diabetes knowledge was retained by the intervention group at 12 month follow-up, whereas it was significantly reduced for the control group
- Many intervention participants were referred to other health services as part of the intervention, possibly due to their previous lack of information on services available to assist with their management of diabetes and associated co-morbidities
- 64% of Control group participants had never seen a podiatrist
- Difficulties with standarisation of foot assessment measurements impacted on usefulness of some key measures

# QUALITATIVE FINDINGS

Thematic analysis of qualitative data obtained in this study has been used to describe the barriers and enablers to good podiatry care for Māori.

	BARRIERS TO GOOD MÃORI FOOT CARE
The barrie	rs identified by participants were summarized into four categories:
\$	Stigma
\$	Unhelpful contexts
\$	Lack of information and understanding
\$	Unhelpful structural processes

## STIGMA

Findings suggest various forms of both external and internal stigma continue to impact on Māori foot health care, each form of stigma reinforcing the other. Despite recent advances in equitable treatment, Māori continue to feel some health professionals treat them with disrespect.

## UNHELPFUL CONTEXTS

A number of barriers to foot care occur in unhelpful contexts which were described as being related to: belief, personal, whānau, community, work and clinical contexts.

LACK OF INFORMATION AND UNDERSTANDING

Lack of information and understanding barriers were created by inappropriate information being given to Māori, which included both culturally and age inappropriate information. Information often lacked a credible source for Māori clients. Health care workers often provide a limited 'menu' of options for clients as they are not always aware of the extensive range of services available.

## UNHELPFUL STRUCTURAL PROCESSES

The present health care system creates barriers to good Māori foot care through unhelpful structural processes. These processes were analysed into six themes: the philosophy of health care; lack of Māori providers; lack of funding sustainability; cost of good foot care services; immobility and lack of service coordination.

### IN SUMMARY

Foot care is a crucial part of the rich tapestry that comprises the complex daily life for Māori who live with diabetes. Participants' stories highlight the urgent need for action that prevents foot pathology from occurring in the first place, rather than treating it once it is too late.

## ENABLERS TO GOOD MAORI FOOT CARE

Analyses demonstrated four key components to "What works best for Māori to reduce the impact of diabetic foot disease?" These key components were:

- Implement health care practices that are relevant and responsive to Māori
- Create helpful contexts
- Implement enabling, focused education and information programmes
- Redesign structural processes.

# IMPLEMENT HEALTH CARE PRACTICES THAT ARE RELEVANT AND RESPONSIVE TO MAORI

By listening to the voice of participants, the identification of enablers to Māori foot care has shown it is important that *Māori knowledge, values, meanings, ways of life and practices inform the provision of foot care*. Applying Māori values and practices enables both clients and providers to provide/receive a service that is acceptable by, and empowering for, Māori. One key area is the establishment of an interpersonal connection between client and health professional that is often lacking in current service provision.

## CREATE HELPFUL CONTEXTS

Helpful contexts involve individuals in self engagement with diabetes to regain a connection between mind, spirit and body. A personal plan developed by the individual and their whānau, in conjunction with a health professional, could facilitate this process, yet very little attention has been given to what such plans are and how they would most benefit Māori. Helpful whānau, community, work, and clinical contexts could also provide realistic and meaningful assistance and support. Engaging whānau and community in diabetes care can have the simultaneous benefit of increasing awareness of their own risk as well as assist with an individual's self management of diabetes.

## IMPLEMENT ENABLING, FOCUSED EDUCATION AND INFORMATION PROGRAMMES

Māori need information shared within a relationship with a health professional that cares about them, and develops that relationship in the right way for Māori. Such a health professional would provide meaningful information to Māori clients as individuals and as a whānau within a given context. Information should contain Māori examples and references that are cultural, locality, age and gender appropriate, and adequately answers their questions in a way that does not trivialise them.

## REDESIGN HEALTH SYSTEMS

Developing a 'whole package' would enable more integrated and coordinated foot care for Māori that was quality assured. Integrating culture into the clinical context requires ongoing training of culturally responsive and competent providers, well as the provision of sustainable funding for podiatry programmes, training and client education. Sustainable funding would provide affordable and accessible support and foot care for individuals with diabetes.

Also by funding preventive health resources (such as lanolin emollient cream) before problems occur, foot pathology may be stopped, or at least halted for some time. Indeed, when the right preventive resources are available and consistently used, problems are less likely to begin in the first place.

## IN SUMMARY

There is strong potential for the provision of easily accessible podiatry services as a part of a team approach through primary health care services to bring about positive outcomes and equitable care for Māori living with diabetes. There is also a need to ensure that Māori whānau and communities have the authority and control with which they can self-empower and take a leading role in the planning of foot care from their perspective in order to implement the findings of this report.

# RECOMENDATIONS OF THIS RESEARCH

The following recommendations have been made for greater effectiveness, appropriateness and relevance of foot care services for Māori, with the aim to reduce lower limb amputations among Māori.

## APPLY MĀORI VALUES, BELIEFS AND PRACTICES IN MĀORI FOOT CARE

There have been some consistent themes across all components of this research that should be addressed in the delivery of all healthcare services and especially foot care services:

- Establishing and maintaining meaningful relationships with Māori
- Recognizing and respecting Māori cultural values, beliefs and practices
- Incorporating these values, beliefs and practices into working with Māori by using Māori models and frameworks
- Reinforcing the need for ongoing education and training in working with Māori in a culturally responsive and competent manner

Critical analysis of the historical and contemporary socio-economic and political influences on Māori

## CREATE HELPFUL CONTEXTS

- Explore healthcare and education options that combine tradition with prevention and intervention
- Engage whanau in healthcare visits, education and development of health plans
- Develop community based (i.e. Māori) health and education programmes based on community identified needs
- Recognition of the impact of the societal, cultural, community and whānau influences on an individual's engagement in the diagnosis and self management of diabetes:

## HEALTHCARE SERVICES

- Ensure that funding bodies and providers actively adopt a preventive philosophy of foot care preventing problems before they occur will reduce the incidence of minor feet problems resulting in amputations
- Explore how health care practitioners and services can establish more meaningful connections with Māori clients e.g. if doctors rotate regularly, perhaps continuity of nurses and front desk staff can be ensured
- Ensure regular health education contact between health providers and Māori living with diabetes in order to retain knowledge about how to manage life with diabetes
- Establish multidisciplinary teams of culturally sensitive responsive practitioners that are able to integrate the services and education they provide
- Ensure that there are evaluation processes for all service and education programmes that test whether Māori responsiveness and relevance is achieved
- Ensure a range of relevant information about preventive foot care that is cultural responsive is available in various forms through relevant media
- Ensure healthcare and education is relevant, accessible, available and affordable to every Māori living with diabetes

## PROVIDE ENABLING EDUCATION PROGRAMMES AND HEALTHCARE WORKFORCE

## HEALTH PROFESSIONAL EDUCATION AND RECRUITMENT

- Education of health professionals to ensure recommendations given by foot health providers to patients is appropriate
- Ensure Māori cultural responsiveness is always undertaken in the healthcare workplace and integrate culture into the clinical context
- Recruit and train more Māori in foot care
- Work in with Māori for instance, contractors to work in with Māori in order to ensure provision of services e.g. podiatry, where they are currently unavailable

### ENABLE MEANINGFUL PATIENT EDUCATION AND WĀNANGA

Plan training programmes and wānanga to meet the needs of local Māori clients and their whānau
 Ensure content and structure of education programmes and wānanga are adapted to meet the needs of local Māori clients and their whānau

#### RESEARCH

- Conduct research that will identify ways to empower whānau and community with the knowledge and skills to understand how to help whānau and community members with diabetes and foot care related needs
- Conduct research that compares the benefits of the creams and socks used in this programme with alternative types of socks and creams to establish the most effective in preventing foot pathology
- Conduct research that will identify how to establish workplaces supportive to the prevention of diabetic foot complications

## CONCLUSION

The findings demonstrate that when one takes the time and energy to develop a deeper understanding of Māori perspectives of health promotion, future activities can be planned in a way that results in better engagement with Māori clients. It is no longer adequate to accept the status quo in Māori foot care. Participants' stories highlight the urgent need for action that prevents foot pathology from occurring in the first place, rather than treating it once it is too late. If we truly wish to make a change in foot care for Māori, new perspectives of health care is the first step to ensuring that, despite a diagnosis of diabetes, Māori living with diabetes are empowered to ensure that their feet remain healthy feet for life.

# CHAPTER ONE INTRODUCTION

A research participant reiterates the importance of the mind/spirit/body interconnection in diabetesrelated Māori foot care:

You have got to try to find that linkage between the feet and our body and the parts that are special, spiritual and tapu. (Interview 009)

As the literature review (see Appendix One) indicates, foot problems related to living with diabetes are an area of particular concern among Māori. Nonetheless, it is well known that foot related pathologies are often preventable, and that healthy feet are an important component of a healthy life. Accessible and acceptable foot specialist services for Māori have the potential to reduce diabetes-related foot problems among Māori (including amputations) and thereby improve Māori health. This research project sought to discover some answers to the question:

"What works best for Māori to reduce the impact of diabetic foot disease?"

### TERMS

For the purposes of this report the following terms are defined:

#### Usual Care

Usual care is defined for the purposes of this research project as the standard level of foot care and advice provided in a health clinic setting to a diabetes patient. This will include referral to a podiatrist when need is identified by service provider.

#### Podiatry

"Podiatry is practised by specialist practitioners who are capable of both independent and interdisciplinary clinical practice. They are skilled in assessing the needs of their patients and of managing both chronic and acute conditions affecting foot and lower limb function. These skills are often practised independently of medical referral and medical supervision. The key role of the podiatrist is to maintain and enhance locomotion function and tissue viability, to alleviate pain and reduce the impact of disability thereby maintaining/improving the quality of life for patients. Podiatric practitioners can provide care to the whole population and so provide clinical services for a diverse range of patients. These particularly include children, the elderly, athletes, people with a learning disability, people with a physical impairment and patients whose health status place the viability of their lower limb at high risk.

Podiatric management is predicated on accurate assessment and diagnosis that leads to the implementation of an appropriate management plan. This recognises the inter-relationship of systemic and extrinsic factors with the function of the lower limb. Effective management is achieved by the implementation of a range of approaches including health promotion, surgical, mechanical and pharmacological therapy. Ref: The Quality Assurance Agency for Higher Education (2002)".

## OVERVIEW OF REPORT

Adopting a multi-method approach, the project involved developing and testing an intervention for the delivery of foot education, screening, early intervention, ongoing care and appropriate referral to other needed services, in a Māori provider setting by a Podiatrist.

Qualitative information was obtained about what community health providers and participants would like to see and the way in which it could be delivered in order to inform the development of the intervention to meet the needs of all stakeholders.

This research involved Māori at almost every step from design to publication, including provision of the podiatry led intervention by Māori health professionals. The research is *about* Māori, mostly *by* Māori, and it is *for* Māori.

Each chapter contains a summary, and qualitative findings chapters contain a diagram of the key findings presented in that chapter. The report begins with a summary of the extensive literature on Māori diabetes related foot health. The comprehensive literature review can be found in Appendix One.

In Chapter Two, the process by which the research was conducted is described with an exploration of the limitations and advantages of the approach used. This discussion is followed by a profile of the final sample in both the intervention and 'usual care' control groups.

Chapter Three presents the qualitative themes identified that describe the participants' views of the barriers to Māori foot health care. The barriers were categorized under the 4 labels: stigma; unhelpful connections; lack of information and understanding; and structural processes.

In Chapter Four, the qualitative themes explaining the enablers to good foot care for Māori are presented and discussed. These included Māori cultural values and practices, creating helpful contexts; focused education, and redesigning structural processes.

Findings from the statistical analysis of data obtained through the survey are described in Chapter Five. This chapter includes information from the research podiatry assessments, interview survey, clinical assessments and podiatry visits.

In Chapter Six, qualitative data collected from intervention participants at the end of the study are incorporated with observation data collected during the wananga, in order to evaluate the acceptability of the intervention to the participants and their whanau.

Chapter Seven integrates the quantitative (Chapter 3) and qualitative (Chapters 4-6) findings and proposes some recommendations. This is followed by a brief summary and conclusion.

# BACKGROUND: SUMMARY LITERATURE REVIEW

(For further information, please see comprehensive literature review in Appendix One)

Illness and death from diabetes complications are common among Māori (Ministry of Health and New Zealand Guidelines Group 2003p). One of these complications, unremitted diabetic foot disease, frequently occurs, and can lead to lower limb amputations (Simmons, Gatland et al. 1995; Simmons, Scott et al. 1995; Simmons 1996). Diabetes-related foot complications are an important health issue because much of the associated severe illness and death can be prevented when people with diabetes receive appropriate preventative care (Armstrong, Lavery et al. 1997; Ministry of Health 2004u). Yet according to Simmons and Fleming (2000) (Simmons and Fleming 2000), Māori are less likely than other New Zealanders to seek ongoing diabetes-related care.

Further, there is a clear difference between risk factors for Māori. The least deprived Europeans are at less risk than the most deprived Europeans, yet for Māori, the level of risk does not change with poverty or wealth. That is, Māori are at the same level of risk, irrespective of their socioeconomic status (Joshy, Porter et al. 2009).

The New Zealand Health Strategy (Ministry of Health 2000a) and He Korowai Oranga Māori Health Strategy (Ministry of Health 2002b; Ministry of Health 2003k) identified the reduction of the incidence and impact of diabetes among Māori as a priority. The New Zealand Health Strategy specifically notes that in order to reduce inequality in health, services must be accessible and appropriate for Māori. Kirkwood, Simmons, Weblemoe and colleagues (1997) identified the need for research on the control of diabetes complications among Māori (Kirkwood, Simmons et al. 1997).

In 1997, Kirkwood and colleagues (1997) made the following statement:

"The recognition of diabetes as a major health problem was accompanied by a call for diabetes education in a form that will generate interest and participation by Māori..."

This research addressed an area of urgent need identified by Māori community members. The project had the potential to provide a method for decreasing lower limb pathology, with wide application among Māori communities. It sought ways in which information about foot care while living with diabetes could be delivered to generate interest and participation by Māori. Further, this research project provided directions to inform Māori health policy, funding and service delivery.

Diabetes has had significant and devastating impacts worldwide. Of particular concern are marginalised populations including ethnic, indigenous, and minority groups. The effects of diabetes not only impacts on individuals but also affects family members, communities and societies with the greatest impacts being physical, emotional and financial. These implications have caused governments worldwide to re-prioritize health strategies to prevent, reduce and monitor diabetes and diabetes-related complications.

A number of successful diabetes and diabetes related-foot interventions have been implemented both internationally and nationally. Interventions, both mainstream and cultural specific, were found to be most successful when tailored, targeted and implemented in consultation with, and for specific population groups.

The review of literature about Māori health highlighted there was no one universal intervention to address all population groups. Findings highlight the need for interventions to be multifaceted and varied using multiple approaches to address specific issues for high risk populations. Interventions designed and developed in partnership with targeted communities and take into consideration the impacts of colonization, determinants of health, the diversity and uniqueness of various populations, as well as being adequately resourced are the most successful in preventing and reducing the impact of Diabetes.

To ensure amputation prevention strategies aimed at Māori will be successful, New Zealand national and local strategies are needed that specifically focus on foot complications as an area of significant concern for Māori. Successful strategies for Māori:

- incorporate both mainstream and cultural components,
- are developed in consultation with Māori communities and stakeholders,
- include messages that are simple, clear, consistent and appropriate,
- incorporate reciprocity and respect,
- support health priorities of most benefit in preventing, reducing and monitoring the impact of diabetes and associated complications, and
- improve health outcomes for Māori.

Interventions incorporating these components benefit specific cultural and minority groups such as Māori, and benefit mainstream populations by reducing the burden of health system and health service costs.

# CHAPTER TWO RESEARCH PROCESS

The research involved a multi-method process based on a Māori theoretical approach. The research process included the development of a year-long lower limb intervention with a usual care comparison group. The intervention was assessed for effectiveness through a number of measures collected longitudinally through an annual structured interview and podiatric assessment. Qualitative information was also collected throughout the project.

## AIMS

The purpose of the project was to improve lower limb outcomes for Māori who live with diabetes. In order to achieve this overall goal, the aims were:

- Develop, implement and evaluate a lower limb intervention for Māori with diabetes, consistent with the aspirations of, and acceptable to Māori.
- Create new knowledge to inform policy, funding decisions, and health service delivery
- Provide a foundation for further research

## OBJECTIVES

The objectives (Ratima et al 2004) of this research were:

- Through focus groups with Māori with diagnosed diabetes and key informant interviews, identify health aspirations, knowledge and perceptions of diabetes and diabetes-related foot issues, barriers and enabling factors relating to diabetic foot self-management and control, podiatryrelated service content and delivery preferences, and, indicators for measuring intervention effectiveness consistent with Māori community values and aspirations.
- Identify key success factors for a diabetes-related lower limb intervention consistent with the aspirations of, and acceptable to Māori
- Develop the self-management capability of Māori with diabetes by promoting independence with foot care.
- Improve the lower limb status of Māori with diabetes, leading to a reduction in amputations for diabetes-related complications.
- Reduce the incidence of unplanned hospital admissions by having an effective intervention.
- Develop, conduct and evaluate a trial lower limb pathology *intervention* acceptable and effective for Māori, which may be adopted by health services
- Develop knowledge concerning diabetes-related lower limb pathology among Māori to inform policy, funding decisions, and health service delivery and is a foundation for further research

## HYPOTHESES

Compared to the 'usual care' control group it was hypothesized the intervention group would, in the follow-up period have significantly:

- better self-reported knowledge and understanding of diabetes and complications, particularly diabetic foot complications,
- better self reported foot self-management,
- better foot health , and
- higher satisfaction with healthcare services for diabetes needs (Penney 2008).

## STUDY DESIGN

The research design was a community trial of a foot care intervention. The proposed project had informative and intervention phases as defined below:

#### **Informative Phase**

- The diabetes related literature was reviewed (Brown and Taupua Waiora 2007).
- Key informant interviews and focus groups were conducted with people diagnosed with diabetes and identified as having diabetes related foot pathology.
- Interviews and focus groups informed the development of a podiatry intervention for Māori. This data was then reviewed for qualitative information.

#### **Intervention Phase**

- A year-long trial intervention for Māori with diabetes was developed and implemented. The design of the intervention was based on the findings of the literature review, key informant interviews and the focus groups, and guided from the Project Advisors.
- Interviews and foot assessments were conducted with a pre-and post intervention group and a comparison group who received 'usual foot care'
- A (brief internal) process and outcome evaluation was conducted.

# ADVISORY GROUP

An advisory group was established to oversee the project (see acknowledgements on page 8). Membership of the group changed throughout the project. The group met regularly during early stages of the project. Teleconferences were held twice, midway through the project and again during the data analysis stage. In addition, a written summary was also forwarded to the advisory group at the end of the project.

# THEORETICAL FRAMEWORK

Patton described how an inquiry paradigm guides research practice (Patton 1990). Research paradigms define acceptable methodologies, research priorities, conceptualization of problems, appropriate methods, and the standards for research quality (Phillips 1987).

At the time when funding for this project was initially sought, a Māori inquiry paradigm had not yet been clearly articulated in the literature. However, a number of themes were identified in the Māori health research literature as providing an indication of the essential features of a Māori inquiry paradigm, and were together used as a theoretical framework for this Māori health research project (Ratima 2003).

The "Theoretical Framework: A Māori inquiry paradigm: A health research perspective") themes were: interconnectedness, Māori potential, Māori control, collectivity, and Māori identity (see Figure 1). These themes provided the theoretical framework for this research project. The themes, rather than particular methodologies, were key to the Māori health research approach used in this study.

THEMES	IMPLICATIONS FOR A MAORI RESEARCH APPROACH
<b>Interconnectedness</b> (Te Ahukaramu 1992; Durie, Allan et al. 1996; Cunningham 1998)	Recognition of links to Māori development. Cognisance of determinants of health. Use of qualitative methods to better ensure context sensitivity.
Māori potential (Te Awekotuku 1991; Bishop 1994; Cram 1995; Durie, Allan et al. 1996; Durie 1998b)	Leads to positive health outcomes for Māori. Contributes to Māori health workforce development. Leads to increased Māori health research capacity.
<b>Māori control</b> (Bishop 1994; Cram 1995; Tuhiwai Smith 1996; Glover 1997; Durie 1998b)	Research is led and controlled by Māori. Projects fits with Māori-defined priorities. Research outputs contribute to increased Māori control over their own health development.
<b>Collectivity</b> (Irwin 1994; Pomare, Keefe- Ormsby et al. 1995; Durie 1998c)	Incorporates mechanisms for input from, and accountability to Māori collectives. Returns information in an accessible form to Māori communities. Produces positive outcomes for Māori collectives.
<b>Māori identity</b> (Irwin 1994; Pomare, Keefe- Ormsby et al. 1995; Durie 1998c)	Consistency with Māori cultural processes. Culturally competent of research team. Maintenance of researchers' connections with their iwi.

FIGURE 1 THEORETICAL FRAMEWORK. A MÃORI INQUIRY PARADIGM: A HEALTH RESEARCH PERSPECTIVE (RATIMA 2003)

This project was reviewed and accepted by the Northern Y Ethics Committee (Ethics Reference No: NTY/05/08/055) and the Auckland University of Technology Ethics Committee (AUTEC Ethics Application Number 07/198).

All research participants were provided with an information letter and an invitation to participate. They were given a consent form, which was signed only after all participants' questions about the study had been fully answered. This process was used for interviews with all key informants, focus group participants, control/intervention interviews and assessments (See Appendix Two for copies of information for participants and consent forms).

In addition to adherence to the above ethics criteria required of research in 'Western' settings, the research process was also ethical in a Māori way; to avoid historical transgressions with indigenous communities:

"To "misrecognise or fail to recognise (cultural difference) can inflict harm, can be a form of oppression, imprisoning someone [or a group] in a false, distorted and reduced model of being", research cannot be "difference-blind" (National Health and Medical Research Council (NHMRC) 2003).

"It galls us that ... researchers' and intellectuals can assume to know all that it is possible to know of us, on the basis of their brief encounters with some of us" (Smith 1999) (p1).

The research was designed by the original researcher to be consistent with the provisions of the Treaty of Waitangi (Waitangi Tribunal 2009) and was maintained in all ways that were possible given constraints of the project.

In order to ensure accordance with the Treaty of Waitangi, a number of processes were implemented. The project was for the most part, led by Māori. The researchers attempted to achieve a research partnership with Māori communities involved in this project. This was reflected in the involvement of Māori provider representatives as co-investigators at each of the three sites. The project involved Māori participation: Māori research participants, Māori members of the research team (six of the original eight named investigators and all but two of the finalizing team were Māori). Further, the project addressed a significant health issue for Māori, and is likely to lead to tangible improvements in Māori health outcomes.

Actions adhering closely to ethical research from a Māori perspective were required throughout every stage of the project. All involved attempted to provide effective interventions specifically designed, targeted and implemented in order to address the significant burden of diabetes and diabetes-related complications among at risk Māori. Consultation with communities, using appropriate language, people, settings and resources as well as incorporating important cultural aspects as a crucial process important for the community and successful project outcomes.

Consultation with the Māori community occurred in the development of the survey. The consultation process led to increased involvement of some providers in the project as co-investigators, and the decision on the clinics that would participate in the project at each site.

Original AUT members of the research team had a long-term relationship with three local organisations. Consultation regarding the proposed project was initiated one and a half years prior to the proposed start date. The proposed project was discussed with a number of people who provided feedback on the project, which was then incorporated.

Almost all Advisory Group members were Māori. Each provider nominated a Māori representative who participated in the earlier research stages as a named investigator. Each provider had consistent Māori input into the research project from initiation until its completion through the Advisory Group.

Further, those participants, key informants and focus group members who had indicated on the consent form that they would like to receive a copy of the research findings were posted a written summary at the end of the project.

Despite working to uphold the principles of the Treaty and to conduct research consistent with Māori ways, more recent writing (Jones, Crengle et al. 2006) demonstrates these attempts to conduct the project according to Māori research principles did not completely achieve such a goal. Nonetheless, the project was conducted attempting to best combine Māori and western ethics. Two processes in which it was essential to uphold Māori values were participant engagement and qualitative data analysis.

## INFORMATIVE PHASE

The informative phase was undertaken to ensure the development of an intervention and set of assessment tools that meet the needs of Māori with type 2 diabetes, and was acceptable to the health service provider and community stakeholders.

## RECRUITMENT

## RECRUITMENT OF KEY INFORMANTS

Selection of 20 key informants occurred through purposeful and opportunistic sampling (Minichiello, Sullivan et al. 2004) of various health professionals. Key informants, considered to have knowledge and experience in the topic area, were contacted personally and interviewed by telephone by the researchers.

#### RECRUITMENT OF FOCUS GROUPS

Focus group participants were recruited through Māori health provider podiatry clinics. Each participant was given initial information about the project by the health service, which followed by a telephone call.

## DATA COLLECTION PROCESS

Qualitative data collection included the collection of taped interviews, the survey and field notes. These data were collected during focus groups with Māori living with foot related pathology, key informant interviews, the education Wānanga and research interviews, discussions with the research team, and in the minutes of discussions with the advisory group and health professionals.

### **KEY INFORMANT INTERVIEWS**

Qualitative data were collected from 20 key informants during a single face-to-face recorded interview, telephone interviews (when field notes were obtained) or during focus groups.

The group resulting from purposeful sampling consisted of 18 people from Māori health providers, iwi and Māori community groups. Represented were Māori diabetes nurse educators, Māori diabetes interest groups, Māori and non-Māori primary health organisations, AUT School of Podiatry, secondary and tertiary health service providers, District Health Boards, private and public podiatry service providers, diabetes service providers, and the Ministry of Health.

#### FOCUS GROUPS

Three focus groups were held. There were 9 in each group. Participants were Māori with diabetes and known foot problems who had accessed podiatry services. Each participant was given initial information about the project, which was followed up by a telephone call. At the focus groups the project and focus group process was explained again to all participants. Each participant gave written consent at the focus group. All focus groups lasted for approximately one hour. Focus groups were facilitated by the primary project investigators. A semi-structured interview schedule was used to guide the focus group (Appendix Three).

## SURVEY DEVELOPMENT

An investigation of barriers and facilitating factors relating to diabetic foot care and management, service content and delivery issues, indicators for measuring intervention effectiveness, and key success factors for a foot care intervention was conducted with key informants and focus groups, using the interview schedule,.

Information from the focus groups and key informant interviews was collated and analysed, and assessed according to the literature and podiatric experience. Key themes were identified. The key themes, along with evidence based literature reviews, were then used to design the foot health survey and podiatry intervention enhancements of the project.

## FINAL QUALITATIVE DATA ANALYSIS

Qualitative data were entered and managed in NVivo (Richards 1999) and analysed using thematic analysis (Browne 2004). Various forms of qualitative information about diabetes related foot health were collected during this research. Qualitative data consisted of recorded interviews with key

informants and focus groups, semi-structured responses recorded during survey implementation, and field notes from the education wananga.

In the tradition of qualitative research, this report allows the participants to 'speak for themselves' where possible. Qualitative analysis was used to bring individual stories together into a collective story. However, the reader must always be aware that Māori are not an homogenous group, and invariably individuals will agree or disagree to a certain extent with the collective stories presented here (Browne 2004).

Qualitative analyses involved two stages. The first analysis was of the key informant and focus group data, used to develop and conduct the core research survey from the perspective of Māori. Qualitative data were later re-analysed to develop themes that described an understanding of Māori perspectives of diabetes related foot health.

## NON-MĀORI DATA ANALYSIS

Throughout the project nearly every team member was Māori, however, the final re-analysis of the qualitative data at the completion of the research project was not carried out by a Māori researcher; a limitation of the qualitative component. At times this created difficulties in the understanding and description of data. The researcher does not speak as Māori, nor at any time to claim or assume more than a basic understanding of Māori concepts, values and understandings. However, as far as possible, all findings have been read and edited by Māori in order to ensure they reflect the participants' voices and meanings have not been substantially changed.

## INTERVENTION PHASE

The dynamics of trust and acceptance are critical in determining participation in research and negotiating access to most people and many communities (Edwards, McManus et al. 2005; Jones, Crengle et al. 2006).

In completing this research, a crucial component was the initial approach when people received the telephone invitation to participate in the second round of interviews. Having not heard from the study for quite some time, it was necessary to re-establish the trust of many participants. The phone call was provided in a friendly, understanding manner and demonstrated genuine connection with the issues important for participants. Research with Māori requires networks of trust are established to achieve its aims. During the interview, the research officer answered all participants' questions, and full explanations were provided in a meaningful way for each participant. People were treated with respect and interest. As the interviewer visited each home, participants became increasingly reengaged in the project as word of the 'reputation' and integrity of the interviewer spread.

Further, it is crucial to note research does not end at the completion of a survey in a Māori community. Having been accepted and trusted, it is then the responsibility of researchers to ensure they maintain this connection and trust is not 'trampled' or 'used' by the researchers. Thus an important component of engagement was the presentation of findings to all participants and interested groups organisations and key informants at the end of the project.

## SETTINGS

There were four settings for this research, two control group (usual care) settings and two intervention settings. In the usual care setting, podiatry services are accessed through general practitioner referral. For this study, enhanced podiatry services were provided by a senior podiatrist and two AUT podiatry students at the intervention settings. Thirty minute appointments were offered at no cost to the patient. An enhanced version of the Wellington Independent Practice Association (WIPA) (Wellington Independent Practice Association 2003) tool was used in the clinics for diabetic foot screening and assessment.

#### 'USUAL CARE' SETTING

For the purposes of this research, usual care was defined as:

What the medical practice would normally recommend for their patients after an annual pedal pulse and Semmes-Weinstein monofilament assessment as performed by practice nurses as part of the national 'Get Checked' programme.

The usual care group received:

- Interview and podiatry (research) assessment using the study interview/assessment form (Appendix Four).
- 'Usual foot care'
- Re-interview and re-assessment at 12 months after the first interview/assessment.
- Between the baseline and 12 month follow-up interview, the usual care group received their 'usual' diabetes related foot care through their general practice health team and any services they may have been referred to by their general practitioner (GP).

#### INTERVENTION SETTING

The intervention group participants were involved in five research processes after recruitment:

- Interview and podiatry research assessment using the study interview/assessment form.
- Clinical assessment for podiatry needs.
- Development of an individualised podiatry plan established in collaboration with the participant
- Enhanced podiatry care (see below) over a 12 month period.
- Re-interview and foot re-assessment at 12 months following the first interview/assessment, including additional feedback questions specific to the intervention (see Appendix Five).

#### ENHANCED PODIATRY CARE FOR INTERVENTION GROUP

For each element of the enhanced podiatry intervention that was proposed by key informants and focus group participants (ie Māori people who were diagnosed with diabetes and identified as having diabetes-related foot pathology) evidence was also collected from the literature to evaluate the potential effectiveness of the intervention (Appendix Six). The intervention group participants were

clinically assessed using the enhanced podiatric tool. The intervention group then received an individual health plan including some or all of the following elements, depending on their needs:

- Diabetes self-management education delivered through education wānanga (Māori-specific approach to group education)
- Proactive measures to facilitate participant attendance at clinics and education sessions, including:
- Appointment reminder calls and provision of transport (or appointment held in person's own home) where necessary
- Service delivery by a range of Māori health professionals in Māori environments.
- Facilitated co-ordination of access to other health professionals and social services
- Provision of skin emollients, hosiery (Appendix Seven for a diagram of the Life-sock), and advice on footwear
- Referral for prescription of foot orthotics

## **RISK CATEGORIES**

Each person was clinically assessed by a podiatrist and provided with a risk category. This number indicated how often the person was to visit the podiatry clinic within the next twelve months before reassessment.

## PODIATRY AUDIT

An audit was also conducted at the intervention settings. The audit involved checking the consistency between Podiatrists at different sites throughout the podiatry assessment process. The audit enabled Podiatrists to check each other's notes and discuss the assessment criteria, and explore any differences. No difference between the two assessments was found.

## EDUCATION WĀNANGA FOR INTERVENTION GROUP

All intervention participants were invited to an education wānanga. Although education was also provided during podiatry visits, the education wānanga was an important component of the intervention. The purpose of the education wānanga was to provide participants in the intervention group with education and knowledge about diabetes and diabetes-related foot conditions and management using a Māori specific approach. The education wānanga was held in February 2008 over two days at a Marae facility at Waitakere hospital. The entire original intervention group of 60 people was invited. Fourteen people attended. Field notes were made, and are discussed below. During the wānanga, core information about diabetes was provided. The manual used for the wānanga was informed by Māori and Māori health care professionals prior to the study's commencement.

## SELECTION CRITERIA

All recorded patients meeting the following four inclusion criteria at any of the participating health provider sites were invited to participate:

- Māori aged over 18 years;
- Diagnosed with diabetes type II;
- Identified as at-risk of diabetes-related foot complications at a diabetes annual review, or with HBA1C greater than 8; and
- Not seen by a podiatrist in the previous 12 months.

## RECRUITMENT OF 'USUAL CARE' AND 'INTERVENTION' GROUPS

Research participants were recruited from four Māori health provider sites. At each practice, a query was conducted on the practice management system database to identify all Māori who met the above selection criteria. A list of eligible patients were generated. The list of eligible patients were not randomised, as assuming a 50% participation rate and given the number of potentially eligible patients, the majority of eligible patients needed to be contacted to meet the target sample size. All participants meeting the inclusion criteria were contacted by phone by the clinics until 120 participants had consented to being contacted by the research office.

A query build was completed by each health service using the following criteria:

- Type II diabetes,
- Māori,
- 18 years or older,
- No DIAP or DM2 within last 12 months. (DIAP is the "diabetes annual project data, a national data collection tool / DM2 is Wai Healths' internal additional diabetes screening tool),
- Previous foot sensation / Pulse NO, as indicated in DIAP,
- Previous ulceration / PVD = YES as indicated in DIAP,
- Or/ incomplete diabetes screening, and
- HbA1c 8%.

Instead of randomly allocating groups, potential participants were allocated to either control or intervention groups according to their engagement with a health service. Thus all usual care control group participants were collected through two health providers and all intervention group participants from the other two health providers. This may have created some bias. The researcher undertaking the baseline interviews was not blinded to which group the participants were in.

Eligible participants were given a brief explanation of the study over the phone by the clinic and their verbal consent to be contacted by the research team was sought. If verbal consent to be contacted was given, the participant's contact details were passed on to Taupua Waiora AUT.

Taupua Waiora staff then contacted each participant by phone to further explain the study, including what participation in the study involved. If verbal consent was given, an appointment was made for a researcher to visit their home or office. An information sheet was given to the participant at the visit.

Written consent was sought by the researcher before undertaking the baseline interview and physical measurements.

#### SURVEY

The survey was reviewed by the advisory group before final acceptance and submission for ethics review. The final survey consisted of 70 semi-structured interview questions and a podiatric assessment (Appendix Four).

The Podiatry research foot assessment provided information about changes in the health of participants' feet over a 12 month period. Among others, the Podiatry research foot assessment obtained data about pedal pulses, circulation, and neuropathology (Appendix Four).

#### BASELINE INFORMATION

Baseline information was obtained at the first interview from both groups. This information enabled participants to be described according to age, gender, condition, education, income, length of time with diabetes, and whether or not the intervention was provided,

Information was also available for the intervention group about risk status, podiatry visits attended, changes in care needs, and change in knowledge, foot care, psychological state, and perceptions of foot care across a twelve month period (See Chapter Five for sample profile).

#### FOLLOW-UP INFORMATION

Participants were followed up 12 months after their baseline with a repeat of their baseline assessment.

An additional section aimed at obtaining qualitative evaluation data was included on the final survey for the intervention group only. This section contained a number of components. It asked about participants' perceptions of the lanolin emollient cream, silver colloidal merino wool socks, education wānanga, and education and referral provided at podiatry visits. Forty-five participants provided answers to these questions.

#### DATA COLLECTION PROCESS

The survey was used to collect information from both usual care control and intervention groups at 12 month intervals. Information included baseline information. Podiatric foot assessments were conducted at twelve monthly intervals. Extensive clinical data was also collected. At the second interview, extra questions about the enhanced podiatry intervention and the research process were included (Appendix Five)

Between the 12 month interviews/assessments the usual care control group received standard foot care, while the intervention group received enhanced podiatric care. At approximately 12 months they were contacted by the research administrator to make an appointment for the second interview and foot health assessments.

## QUANTITATIVE DATA ANALYSIS

All completed quantitative information from the survey and foot assessments were coded; quality checked and double entered into a SPSS database; and later analysed and presented using SAS version 9.2 (<u>www.sas.com</u>). Clinical data were entered into Excel and analysed using SAS version 9.2 (<u>www.sas.com</u>).

Models to examine the effect of the intervention trial on key outcome measures were analysis using repeated measures ANOVAs or Logistic regression models, depending on whether the outcome measure was dichotomous or ordinal. The models were adjusted for age, sex and years since diagnosis of diabetes.

# SUMMARY OF RESEARCH PROCESSES

The multi-method research process involved the collection of a range of qualitative information, which was used to design a survey and also to provide more in-depth explanations of Māori understandings of foot care. The survey was completed by 97 Māori before and 12 months after the intervention. A podiatry foot assessment was completed for each participant at the beginning and end of the study. Participants received either usual foot care or enhanced podiatry care.

# CHAPTER THREE QUALITATIVE FINDINGS: BARRIERS TO MĀORI FOOT CARE

# INTRODUCTION

I think the first stage is to ask the people and how they want the service delivered. So that is the first fundamental step. The second is to develop service delivery models around those needs... (Interview 008)

This research project aimed to fulfil the above participant's recommendation: first, to ask Māori living with diabetes about foot care. Second, to listen to what Māori living with diabetes have to say; and third, to explore ways in which Māori perspectives collected can be acted upon.

The following participant noted the practical realities of obtaining diabetes related foot care and preventing amputation, given the complexity of daily barriers Māori experience.

There would be five things. Those five things are firstly the person being educated about what they need, why they need it, when to get it and who to get it from. The second barrier would be transport. The third would be the costs of visits. The fourth would be having ongoing support and follow-up and the fifth would be the socio-economic environment that the typical Māori diabetic person resides in, which results in their diabetic foot care coming in at about number 93 on their list of priorities because they're trying to hold down a job or on a benefit and really lack lots of other priorities in their lives around income and food and housing and transport and childcare. Those would be the 5. All of them interact; none of them are in isolation. (Interview 013)

This section of the report focuses on the findings of the analysis central to the prevention of *diabetes related foot pathology*. The first section describes *barriers* to foot health from the perspectives of the participants.

The barriers participants identified are described according to five main themes.

- Stigma
- Unhelpful contexts
- Lack of knowledge and information
- Unhelpful structural processes

# STIGMA

Multiple forms of stigma are known to be experienced internationally by indigenous peoples (Smith 1999). This research demonstrated that stigma continues to impact Māori foot health care. Two forms of stigma are described by participants. These are external stigma, such as those found in interactions with health professional and within the healthcare system; and internal stigma.

## EXTERNAL STIGMA: HEALTH PROFESSIONAL TALK

Although participants acknowledge that respectful care is given by many health practitioners:

My doctor is excellent, now and again we have a little row, but I listen to her. (Focus Group Participant)

Participants indicated the way a number of health professionals' interact with Māori during clinical interviews, including the way they respond to Māori requests for knowledge and information about foot care, is frequently perceived to be stigmatising.

Some health practitioners behaved in a manner described as minimising the knowledge and experience of Maori, and was perceived as disrespectful and judgmental. Participants indicated that they feel these negative judgments are the direct result of negative attitudes toward being Māori, being overweight, being an older person or any combination of these.

We're quite intelligent people and we think that we've got our diabetes under control. Basically they give us the medication and say, "you're a diabetic", and lay it down like we're children. We're adult people. (Focus Group Participant)

Another thing too is the attitude of a lot of the nurses - how they treat the older people. They treat us as children. We've been around a long time and worked under more stress than any of these people will ever know. They talk down to us like babies. I think we need to be talked to like adults. (Focus Group Participant)

Despite changes in health care to increase cultural, body perception and age related understandings and respect, along with greater comprehension of stigma and its communication, participants described 'feeling disrespected', 'being told what to do', and 'treated like children' when they receive healthcare for diabetes, and foot health in particular. Stigma was especially evident when Māori described what happened when they asked questions.

## TRIVIALISING MĀORI QUESTIONS

The stigma described by this group within health professional interactions was most evident when Māori clients asked health professionals questions about their foot and health care. When asked clinical questions related to their health by a client the health professional may respond in a number of ways. Health professionals can provide accurate information as many times as questions are asked, in a way that the listener can understand and apply the information. However, a number of participants noted, some health professionals negate their questions, often in a misguided attempt to be supportive or reassuring. When Māori do ask questions in the clinic, participants noted their symptoms and requests were often trivialised and brushed off as unimportant.

I go there with my hands numb but they just say "take these pills" and they were just (very offhand) and I thought, "gee you need better pills than that, what is the cause of the numbness?" (Focus Group Participant)

I have 14 odd pills I have to take. I don't even know why I'm taking them. There's some there for my heart, the diabetes, the pain from my operation. (Focus Group Participant)
Participants talked about how some professionals look disinterested when they are asked questions, provide no answers or give meaningless reassurance. Therefore, Māori may not receive the information needed to understand what they should to achieve foot health.

It may take more than one korero before you get to understand it. I feel it is our right. Why are you taking my blood, what's it for, and what are those results going to tell me. But nobody actually teaches you about your diabetes for instance. They tell you the results - but there is no education, no time to understand it. (Focus Group Participant)

Simple, meaningless answers such as "take these pills" are inadequate, disrespect Māori as 'unworthy' of a proper explanation, and ignore the trauma of people's experience of diabetes. 'Trivialising' responses to questions tends to stop people asking for the information they need from the health professional. In addition, trivialising responses result in a sense of alienation and disconnection from one's own condition and understanding how they can help themselves, and from health professionals being accountable for the information that is given.

Health professionals confirmed what participants living with diabetes said, and also noted there was a lack of critical knowledge sharing with Māori clients.

Somebody, somewhere actually told them what was going on about feet. More often what we find is that we send people off but we don't tell them 'why' they might be ending up with problems with their feet, or how those problems might present, and that funny looking bit of black skin off their cold blues toes is actually a real problem. So you can often find people come in and they've already ulcerated and they've got diabetic skin ulcers that have already developed. So there's a lack of communication about what to expect and why it happens. (Interview 019)

Another interviewee noted doctors do not necessarily know how to present information appropriate for Māori. This combined with a lower expectation Māori may have developed over time, dismisses their knowledge needs. Thus they have been conditioned to have low expectations of how 'well' their feet should be.

That may not be the way in which GPs are good at giving that information. There maybe a mismatch there. (Interview 016)

Māori living with diabetes are not made aware of the warning signs when something is going 'wrong' with their feet or health in general.

It is important to educate doctors on how to provide critical information appropriate for Māori and how to respond effectively to questions initiated by Māori. Further, it is crucial to teach Māori how to identify the warning signs indicating that they need to take action to prevent small problems from becoming large ones. However, having been taught warning signs and taken preventive action, such action may require assistance from people within the healthcare system, where stigma can be evident.

### STIGMA WITHIN THE HEALTH CARE SYSTEM

Some participants implied the services provided to Māori are not as high a standard as those received by other New Zealanders, and indicated this is a stigmatising process.

One health professional noted many Māori in Auckland have diabetes (or similar health issues) but remain undiagnosed as they are not enrolled with a PHO or GP and there is a lack of a screening programme. One health professional noted the number of Māori who attend to get a free check is lower than for non-Māori.

Within Auckland - not all Māori are involved with a doctor or a PHO, so they don't access and are not in touch with the system and don't access services that many take for granted. For example in Auckland only, according to statistics only 60% of around 30,000 people are enrolled with a PHO or GP where once they're in touch they get referred to these types of services. This is a fundamental problem. There is not a screening programme currently active in particularly Auckland so if there's plenty of undiagnosed Māori and haven't been screened then obviously not all Māori would be referred to podiatry services. So I think those are the two main things that we don't have access to health services in general or we have poor access to health services in general and that there is no active screening programme and podiatry is one component of the overall service.

Another participant also noted the accepted 'get checked' rates for Māori are set at a different (ie lower) rate than for non-Māori. This participant went on to say this is unquestionably acceptance of a lower standard, and to accept a lower standard is an inadequate response to inequity.

We're just accepting a lower standard really. I don't know what impact that has on Māori themselves. ........ I thought to myself, "Why am I saying that this is fine?" (Interview 007)

Thus, it is important to review the *quality* of foot care services provided to Māori, and explore ways in which the structure of the healthcare system itself may facilitate or sustain processes that are not equal.

Many things caused a sense of being judged negatively externally, but negative judgments also came from within.

#### INTERNALISED STIGMA

Various forms of stigma seemed to compound for Māori with diabetes (being Māori, overweight and/or older). Whatever the cause, Māori in this study noted feeling negatively judged when things related to a diagnosis of diabetes went wrong. Uncovering internalized forms of stigma is an important process as people who are stigmatised tend to subconsciously reiterate the external prejudices applied to them (Goffman 1963). Negative stereotypes explained by participants specifically related to self-perceptions of their personal care of diabetic feet.

... if you do it wrong, people say you've failed to manage yourself, you have poor self-management. There are a lot of judgments around diabetes. "You're like that because you are fat." "You eat the wrong foods". (Interview 0004) Indeed, internalised negative self-judgments are a major barrier to seeking assistive services for foot health.

There is a bit of a stigma of not looking after yourself and not looking after your feet, I think that is a barrier, as well as feeling bad about letting your feet get into a problem. Interview 004

Many Māori patients will have seen or are much more likely to have seen bad outcomes. The Māori experience of what is normal may be much worse than the Pākehā experience of what is normal in terms of diabetic foot disease. So Māori patients may have a lower expectation - which is probably correct given the reality in terms of Māori experience with the health system. (Interview 016)

Some participants living with diabetes commented that when they disclosed the nature and degree to which their feet have been affected, they feel a sense of 'blame', and the condition of their feet will be used as evidence to indicate that they 'don't do the right thing' or 'do not do it well'. Subsequently, all forms of helpful assistance become more difficult to obtain.

Participants also noted they were embarrassed to show their feet, especially if they are not in a healthy condition. Feeling stigmatised, they become shy with regard to telling people about problems they might not notice until they are in quite late stages. As the sense of stigma grew, whether potential or actual, they increasingly became afraid to speak up when foot problems began, or contemplate the embarrassment they would feel if they sought help.

Minor foot conditions, bruises and scratches became significant while shame and guilt prevented people seeking help. Therefore, Māori were often seen in later stages of the disease, when minor situations had become so serious they could no longer be avoided, and preventive action was no longer possible or effective. In some cases the consequences for lead to major action, including amputation. Thus in a number of ways, Māori absorb, reflect and internalise various forms of stigma and develop subsequent lowered expectations of their health and health care. It is important to note many of the barriers discussed in later sections of this report are connected in subtle ways to stigma.

Parallel to stigmatizing processes, Māori at risk of foot pathology encounter a number of unhelpful contexts in their daily lives.

## UNHELPFUL CONTEXTS

Participants repeatedly described certain contexts as unhelpful. An unhelpful context is a situation that does not support a person living with diabetes to maintain healthy feet. These unhelpful contexts included ways in which individuals perceived themselves, personal contexts, various aspects of whānau, community, work and relationships with practitioners. Six forms of unhelpful contexts were identified:

- Belief
- Personal
- 🔷 Whānau
- Community
- 🔷 Work
- Clinical

### **BELIEF CONTEXTS**

I've noticed that Māori people are quite specific about their feet and there's that whole component about, and it goes back to being on the marae where you're waewae tapu, you know that whole presence - because it's our feet that carries us across there. So to them it's very much an important part of the body. It's also part of the body that they don't want to have mucked around in terms of mainstream services. (Interview 009)

It is possible long-held Māori traditions and beliefs may create barriers to foot health. For instance some specific barriers related to Māori belief systems were identified by the participants, such as it may be less likely for Māori to want to work with other people's feet, to show interest in their own feet, to wear protective footwear at all times, or to ask for help with their feet because of traditional understandings related to the sacredness or uncleanness of feet.

It is important Māori are empowered to explore such beliefs within their history, tradition and culture. In this way Māori can discover whether there are contexts that may negatively impact on foot health, and subsequently determine how the effect of any such belief or tradition can be minimised to enable good foot health for Māori with diabetes.

## PERSONAL CONTEXTS

Three predominant personal contexts that may be identified as barriers were described. These were related to unhelpful thinking processes, a lack of acceptance of the diagnosis of diabetes, and fear of the healthcare system.

- Unhelpful thinking processes
- Lack of acceptance of the diagnosis of diabetes
- Fear of the healthcare system

UNHELPFUL THINKING PROCESSES

In addition to internalised stigma, the thinking processes around having diabetes may be unhelpful to taking the actions that are needed, and to acceptance of diagnosis and change.

It is well known, even when people know what to do, they do not necessarily do it. This occurs across a range of health behaviors, and was also reflected in the data. There was a clear difference between what people know, and what they do.

Lead us not into temptation! (Focus Group Participant)

It's often easier to ignore something than to face up to the reality of what's likely. If every time your blood sugar was up you got a headache, it would be relatively easier to manage because people would do something about it. But when people feel perfectly well...Until they get a complication or really taking it on seriously - so you get around to doing it, maybe one day. (Interview 014)

There's less acceptance of the need to be proactive. (Interview 014)

Some participants talked about the barriers they put up as one of the main barriers to adopting helpful changes.

#### Q: What stands in the way?

A: Grief and loss, lack of support, **me** "...the barriers I put in front of me. (Education Wānanga Notes)

They probably do it all the time and it can be depressing for them. I've come across those who are getting sick of it. (Interview 05)

We used to put butter on toast that has already been buttered. It sounds like we know what we need to do, the difficulty is actually doing it. It's not easy to stick to it. (Focus Group Participant)

I find sometimes too when I finish work I can't be bothered, I'll just do a quick meal...... My ideal thing would be to put all my meals on a week and get them out in the evening, but I haven't yet got around to it. Sometimes it's just hard putting your own things together. (Focus Group Participant)

#### LACK OF ACCEPTANCE OF THE DIAGNOSIS OF DIABETES

Another participant noted that often Māori do not accept a diabetes diagnosis, nor do they accept the impact of uncontrolled diabetes on their body and wellbeing. As a consequence, knowing one has a medical diagnosis does not mean people are able to connect that diagnosis with what it means for them.

Chronic diseases - you don't accept [the diagnosis] well. It's a psychological thing - about grieving. ... ... I do not think we are trained enough to accept that they have a chronic disease and management will change your life. ... ... If we understand that then we can pick it up, but if no one is able to help us...[pause]. It's like counseling. You have got to be helped through, go through a new way. I think we haven't studied it enough. Key factors to reverse that? Addressing that? I think we need to skill our doctors and Māori community workers [to understand that]. Polynesian is different than Pākehā. We have to be trained - as that would make a big difference. We are only trained in the physical. Not with the psychological difference with Māori the dealing with the information. Training regarding psychology - it's a higher level but it needs to be worked through culturally. How do you train for that? It's about knowing the psyche isn't it? A lot of it to me is external factors. How people feel in society like powerless, how their values are reflected back to them. How people do or don't see themselves in society. (Interview 003)

Probably denial! It's the self-image of ourselves that we're very robust people and athletic fit people. We have a strong image of ourselves. And then you're not even out of your 30s then you've got diseases coming at you. Fit and strong and quick and alert going into your late 30's around your 40s taking on chronic disease. Too quick the transition. The transition that people have to carry out... ... it's probably denial. (Interview 003)

Others felt that some Māori have no insight into the reason for many of the things that they are asked to do, because they lack understanding of the body and its functions, and therefore why it would benefit them:

If I know something is not good for me I'm going to eat it anyway because I like it... ... it's about learning about your body, what makes you feel good, and how you lose weight., Understanding your body is the biggest problem for Māori. (Focus Group Participant)

A number of people explained they do not have a sense that one's own eating behaviours are connected with diabetes, and that ultimately having diabetes relates to their own foot health. Participants talked about how there was an increasing sense of alienation from one's diagnosis and body, which ultimately fragments the spirit:

[The education we are given] freaks people out. Your body becomes your kidneys, and your eyes, and your feet and your sugars. Breaking people up into little bits! (Interview 004)

#### FEAR OF THE DIAGNOSIS

The diagnosis of diabetes itself can raise fear in Māori. Fear creates denial, which results in a subsequent resignation.

I think that one of the barriers to healthcare is fear. Fear of what diabetes means. (Interview 014)

A lot of Māori have relations, who have suffered consequences. So fear plays a large part, and ultimately ends up as non compliance ... (Interview 014)

From the few that I've had I've gone to their homes and they are not home, only a few. They're just scared of hearing - of what you have to tell them. They've had it told to them once before from their GP, and maybe they are not ready to accept what they're going to be told, and not sure. Generally people really want to know what it's all about. (Interview 002)

Diabetes, particularly foot problems present late. So it's late presentation so it's about patient's awareness and then it's about fear. Fear around coming into a hospital in terms of, if I had foot problems are they going to chop my feet off and stuff like that. That's sort of like the common thing that's come through with a lot of my patients around their feet, because those patients that I have known that have got diabetes and I know other people, and when those other people are presented to a hospital and gone into the podiatrist clinic or high risk vascular foot clinic. Ultimately over a period of time sometimes but not always, those people have ended up with amputations, and that's created a fear, a fear with people who are well, and about, oh my goodness if they touch my waewae or something, you know that whole issue around the fear of losing their limbs. That's quite a huge barrier. (Interview 009)

Diabetes was described by participants as an 'attack on self esteem'. Diabetes challenges the sense of self as a whole and healthy entity. Participants describe the diagnosis as causing a loss of a sense of youth, a challenge to a sense of personal strength and evoking fears, such as fear of the consequences of the diagnosis like eventual amputation. Participants stated that when one is relatively young, it seems the ageing transition has been speeded up, that the body is failing and its strength, endurance and resilience are questioned.

A part of being afraid of being diagnosed as having a chronic illness such as diabetes is being afraid of the health care system.

## FEAR OF THE HEALTHCARE SYSTEM

Once diagnosed with any significant health condition, 'membership' of western health care systems becomes seemingly automatic. Participants described fear of the health system in general, including its association with illness.

A general kind of fear of the whole healthcare system and the healthcare providers, with its association with sickness and illness. (Interview 001)

Others discussed a fear of an anonymous healthcare system that monitors and records many forms of individual detail. One family member and a nurse at one of the health providers noted people are afraid, or do not like, the sense of 'big brother' that comes from modern record keeping systems and the use of computers. Participants described having a sense being 'overly visible', 'under observation' in a 'big brother' way.

In particular the file - she didn't like them using them and I think she just did not trust them. (Interview 002)

In contrast, others described feeling 'invisible' within the healthcare system, and of 'going nowhere'.

Fear for many Māori with family histories of diabetes could be partly associated with knowing about the difficulty of negotiating a large, seemingly anonymous and bewildering system. Yet others may be afraid when they enter hospital they will leave like their relatives before them, with frightening consequences such as amputations.

Others noted they were skeptical about western systems of health.

The other thing I think that Māori have less acceptance of western medicine than western people, perhaps a degree of skepticism and maybe a greater acceptance of other forms of healthcare, or alternatives. There's less acceptance of the need to be proactive. (Interview 014)

It would be valuable to disseminate information about why records are important and how Māori can benefit from their use. It is also crucial to develop information systems that are not 'big brother' type systems but provide information useful to, and supportive of, clients.

## UNHELPFUL WHĀNAU CONTEXTS

Although acknowledged and recognised in Māori contexts whānau and community are not separate, as whānau embodies a wide range of relationships. For ease of explanation whānau and community are nonetheless discussed separately in this chapter.

A number of whānau and community contexts were found in the data to be unhelpful to selfmaintenance when one is at risk of diabetes related foot pathology. These contexts included:

- Lack of whānau support
- Prioritising Whānau
- Whānau jokes
- Whānau history

#### LACK OF WHĀNAU SUPPORT

The barriers would be not having the support of the family, where they are, where they're living. That can be a barrier. They get frustrated can't be bothered, not getting support from their whānau, just to help them care for their feet, doing it the rōngoa way too, getting this and that to help like the kawakawa, collecting it, bringing all that's needed to do their feet. It really depends on the person and how they look after themselves. (Interview 005)

For some, a lack of whānau support is evident. For others, while providing support to the whānau, they do not consider their own health needs.

#### PRIORITISING WHĀNAU

Despite the desire to act on what one knows, often there are major constraints to this. One of the important barriers by which many Māori are challenged is when they prioritise whānau/family needs above their own need for self-management. This is partly because the embedded cultural meaning of sharing and caring, in addition to the complexities of their daily lives.

When I have my mokos around they're my first priority. So I feed them and I wonder, where's my kai? (Focus Group Participant)

As far as Māori are concerned, there are other issues than self-care, other issues like whānau. I can give you anecdotal examples of a woman who has a child with real health needs - and she ignores her own health needs in preference to concentrating on the child's needs. I know that people have large families and they're more concerned with putting food on the table and maintaining harmony in the family than looking after themselves Interview 014

... ... self care is something that just gets put over there "my whānau comes first", "my church comes first." I think because a lot of it is that overall people are providing for their family, they're providing for their mokopuna, they're just trying to get on in life. When it comes to one's self it's kind of like, "I'm okay, I'm fine, I'll be alright", and they're here and the whānau is around them. (Interview 009)

Most of the Māori people our age are there to look after our mokos (grandchildren) so that our kids can go to work. ..... "Caring" is not caring about themself!" (Focus Group Participant)

You find in most cases the old people are going to take the mokos and awhi them along. They're doing that and looking after the mokos while they're doing for themselves. They'll eat whatever because that's a full-time job looking after children. We've done it, we've done that looking after our families but then we got to turn around and do it at our age. They [we] need help! (Focus Group Participant)

People do not have an understanding of how they can be <u>both</u> self-caring while fulfilling their whānau role and demonstrating their love for whānau.

WHĀNAU JOKES

Simultaneously, participants noted despite assumptions whānau are helpful, whānau can be challenging in multiple ways. For instance:

I have to tell my lot at home, "Hey, scrape your food into the bin" because it would be in my trap before it gets in the bin (Focus Group Participant)

Some participants also noted whānau members often tease about diabetes. Teasing, no matter how well meant, can be disempowering, off-putting and even at times hurtful when people are trying to maintain a diet or a healthy way of life.

So they're teaching everyone not to slice out about what's good for you. (Focus Group Participant)

WHĀNAU HISTORIES

There are historical ways in which whānau operate, how things have always been done, what is done where and how within the whānau. This whānau history often can create more challenges for some people. Two ways in which whānau history was unhelpful was learnt negative behaviors and resignation to a diagnosis of diabetes.

## Learnt Behaviors

My mum was diabetic too. I'd copy what she used to do, eat cakes eat all the wrong stuff. She was my role model. I copied what she was doing. A lot of it is to do with education and they didn't have it, I wish they did. ... I don't want my kids to have it. (Focus Group Participant)

Our grandmother and grandfather were really huge people and my cousin says it's the first time in her life she's been under 180 kgs, before that she was 200 plus. Her sisters are all like that. My grandmother was a big lady. When they feed you they just <u>feed</u> you (Focus Group Participant)

For years and years I never used to eat breakfast and it was there in front of me... ... at home or daily work I might not have breakfast I might have a coffee, tea. My mum and them used to have a smoke and a cup of tea, first thing in the morning. During the day they might have a kai about 11 and then the next kai they might have about 4 and the next kai might be about 8, 9 o'clock at night. So it is times that they don't eat, and then sometimes they don't eat and they get really hungry. (Focus Group Participant)

I don't know if it was passed down because my dad was always gone before sun up ... he would get back to the house about 9 [pm] and then we would have something to eat ... If I'm gone early in the morning, I'm normally gone by 5. I might get there around 9 o'clock and I'll want a cup of tea (Focus Group Participant)

## Resignation

Expecting a diagnosis with diabetes because many whānau members have had diabetes, Māori can be resigned to the fact they will also get diabetes. Also described was 'shyness' resulting in personal difficulties for many people in 'coming forward' and asking for help.

Perhaps the turoro tends to say, "Kei te pai, a te wa", it could be that in saying that, they probably may lack better education around that. When I say that, I just tend to think of a lot of the whānau I mingle with. (Interview 015)

What goes with that could be a degree of, "What will be, will be". A resignation about the illness and that has to do with having seen what's happened to others. (Interview 014)

The above quotes illustrate how eating patterns, which do not reflect accepted guidelines for people living with diabetes, emerge from learnt whānau patterns or a learnt resignation because of acceptance of a genetic imperative.

Nonetheless, we must be cautious and remember that Māori are not heterogeneous, or all the same. For instance, one participant talked about whakamā (shyness, shame or guilt) around involving whānau, not wanting whānau involved and did not want to inform whānau because they 'don't want them to know'. No 'one size fits all' - it is most important to assess the needs of each person and establish genuine connection before any action.

According to the data, an important and powerful barrier to the majority of Māori diabetes care continues to be when the whānau are not involved and engaged, when they do not understand the impact of diabetes and a joke about the diagnosis, and when historical whānau patterns are difficult to overcome. Very little attention has been given to whānau and how whānau can successfully engage in diabetes care (Brown and Taupua Waiora 2007). Further, there is minimal information about how whānau can be assisted to be involved.

#### COMMUNITY CONTEXTS

Despite the fact community involvement is mostly talked about as a 'good', increasing social support and decreasing isolation for people with a chronic illness, some participants reported community settings can create their own challenges and choices for people with diabetes.

Managing my diabetes I find it quite hard, when I go to Hui, and the kai that's on the table, is all fatty stuff, it's just a way of life on the marae. I know there is kai on the table that is good for our diabetes. The invitation that it's put in front of you is also stronger too, than what the diabetes kai is. Yes we all stand there (I'm in this Ropu kaumatua group) and we're standing there and we all know what we're allowed to eat, what we're supposed to eat. But the temptation is there, we all know, and that when we talk about kai .....but it's just temptation when it's put in your way it's like the devil saying yeah eat that - you'll be alright you'll go back home and you'll get back on to your diet. (Focus Group Participant)

Communities are often highly supportive to people living with diabetes, but can also be very discouraging and force a person who is trying to live a healthy lifestyle into difficult choice situations. The data highlight the question: How can community contexts best facilitate healthy choices for people with diabetes?

Unhelpful contexts are compounded when a person feels a sense of disconnection in their work environments and from health care professionals.

#### WORK CONTEXTS

Very little of the data discussed work environments and how they impact foot health. A possible reason for this is the age of the sample. As most participants were older or retired, work context were

not a priority for them. Nonetheless, a small amount of data highlights the importance of exploring this very significant area in the lives of people with diabetes-related foot pathology. In the following quotes, for instance, work-related eating patterns can either reiterate whānau history and/or create unhelpful contexts for people with diabetes.

If I'm in a meeting it might be 11 or 11.30 before we get something to eat. It would normally be finger food, and the things that we eat as the finger food are all hot foods [ie cooked in oil or fat]. (Focus Group Participant)

Yes it would be an issue here as well [at work in a health care setting] for kai hakari for farewells and things. We have this beautiful spread catered by whoever, they always do have the good kai. There is a mixture of good kai and bad kai - I'll put it as bad kai. We all know that and we say, "Oh, we shouldn't have eaten that. Oh well...kei te pai". (Focus Group Participant)

Work situations such as eating patterns and foot safety can have considerable impacts on the foot care of a person with diabetes. This raises the question of what impact work environments have on the foot care of people with diabetes, and whether work environments can create healthy or unhealthy contexts for diabetes-related foot care.

## CLINICAL CONTEXTS

Participants explained they frequently lacked of a sense of connection with their own health care practitioners, such as with general practitioners (GPs). They described a sense of invisibility to their health practitioners as they often received impersonal care from multiple health practitioners, leading to no link to a service. The consequence of feeling invisible and a lack of connection is not feeling obligated to be forthcoming.

Down here we see different doctors. We don't actually see the same doctor who knows our family history. If I went home the doctor up there, he knows I was born there and what sickness I had. He knew my mum's history, my grandfather's history, my family's history etc, so one person's got knowledge of all this whānau medical history. Down here we might see somebody one day and the next day we might see somebody else, we never see the same person. When I used to go to the specialists at ..... they used to say, "Is your doctor so and so?" And I'd say, "Yeah". It's probably not. Perhaps that was the first doctor I saw when that person referred me for diabetes - and so I've not seen her now for a long time. (Focus Group Participant)

You come back and see your doctor and they don't even know that you've been [for certain tests]. You tell them, "I went to see this person", but they don't know about it.

One of the consequences for clients is that there is neither consistency, clinical follow-up, nor a global view of individual health needs. Clients often do not feel a sense of being 'known about' by health professionals nor connected to them.

Important ways in which fear and resignation are addressed are the development of knowledge and understanding.

## LACK OF INFORMATION AND UNDERSTANDING

The people aren't very well educated on the importance of what they need to do, why they need to do it, and how they can do it. (Interview 013)

Having knowledge, information and understanding is an important to having the personal power to act. Yet the data indicated Māori are often perceived to have inadequate knowledge and information.

It is important people have an understanding of the condition with which they have been diagnosed; are able to identify their own triggers and warning signs, that they are aware of where and how to get support, know who to ask for help and when to ask; and how to get the most appropriate assistance. It is also essential to provide information in ways that can be heard, understood and implemented (Russell and Browne 2005). One (Focus Group Participant) noted that they have "no place to go to learn about diabetes" Another noted that when they found out they had diabetes there was no kind of follow-up in relation to the diabetes.

Yet the best possible and most up-to-date evidence and information is not always available in meaningful forms or culturally and age appropriate. The content may be inadequate and the source of information may not be credible to Māori clients.

Barriers related to information and understanding was two major themes:

- Inappropriate information
  - o Culturally inappropriate
  - o Lack of credibility to Māori
  - Age inappropriate
- Limited Menus

#### INAPPROPRIATE INFORMATION

Inappropriate information provided in education programmes or clinical settings takes many forms. The data demonstrated participants had received information that was culturally and age inappropriate, from a source lacking credibility, and as one participant stated, according to 'a limited menu'.

#### CULTURALLY INAPPROPRIATE

For some, information was not provided in te reo Māori. Where possible, participants who spoke te reo well preferred to obtain information in te reo. Nonetheless, they recognised many Māori do not speak te reo well. Participants acknowledged that it was necessary to accept a compromise. Most important was information be meaningful to Māori recipients.

Māori appropriate language - but not necessarily Māori language - but language that Māori understand. (Interview 006)

Knowledge was described as inappropriate when professionals made suggestions to Māori about things they 'could/should do' about their foot care or diabetes – yet those suggestions were not

appropriate. Information was given in general ways, not taking Māori preferences into account, so was often of no use to some patients.

Māori are often shy to go to gyms or they don't like to go to public swimming pools to try and do their exercise because they don't like to expose their bodies, and all of those are peculiar I think, to Māori. (Interview 14)

Those issues in regards to wearing shoes in the house including slippers when people might be inside, [knowing that] it is not culturally inappropriate. (Interview 001)

Further, participants highlighted the need for information to be relevant and useful to Māori that they can put into action. Yet data showed information provided by health professionals is frequently inadequate and did not provide people with information in a way that was of relevance to the participant.

A lot [of clients] aren't medically minded in terms of plain education. They're just not – it's a big leap. What is glucose, what is sugar, is it the sugar I eat, all of these sorts of questions that other people probably know. Why does my sugar level go up when I'm eating no sugar, but geez I'm eating tons of fat? Those are little basic questions. A lot of non-Māori also need that. Interview 011

Although people may be given information, it is not necessarily in a form the client can relate to or addresses their own questions. Rather it is the information the health professional decides is important. A further barrier occurs when the source of the information is not one that is credible to Māori.

#### LACKING CREDIBILITY TO MĀORI

Health professionals frequently assume, without evidence, that they provide information to clients and they are a useful resource for clients.

In some situations information was not provided at all.

Q Where do you go to get information?

#### A: Nowhere. Nurses don't tell us about diabetes. (Focus Group Participant)

While some health professionals do not provide any information, others provide information that is not credible to Māori clients. One of the reasons information may not be trusted is, as noted previously, there is a lack of relationship with the client. Relationships are crucial for Māori, and information may not be accepted because the person providing it has not (yet) established a connection with the client.

To be Māori themselves. To know what one goes through. [They have] to be culturally aware and culturally sensitive to [Māori] needs. Look at the appropriateness of the person, to see the client - someone from the community - someone from the Hauora to make first assessment as you have to gain their trust first, and you take it from there. (Interview 005)

This report shows it is vital to train and inform health care professionals, including doctors, nurses and podiatrists, about what is the best and most appropriate way to present information to Māori in a credible way.

#### AGE INAPPROPRIATE

A participant noted there may also be generational differences in the barriers that people may face. According to participants, the ages of both a patient and a health practitioner makes a difference to how information is interpreted.

I think a big one is whakama. They feel stupid and a bit embarrassed to say, "Yes I have my diabetic testing pen, but no one has told me how to dial the needle down properly". I think that's certainly one thing is - it's embarrassing [i.e. to admit lack of knowledge]. I'm talking mainly older generation Māori here, not younger because the younger have the opposite attitude which is, you give me everything because I deserve it. But it's the older generation who are generally the type 2 diabetics anyway. They can be very much, "We don't want to take up this ladies time, come on lets go, everything's fine". (Interview 011)

They don't like to be a bother, it puts them off a bit. (Interview 011)

Other participants, both living with diabetes and health professionals, stated older clients will simply agree, even if they do not understand what is said, in order to be polite.

A further barrier occurs when clients are not given information about the diverse variety of services and information available or possible.

### LIMITED MENU

Participants made it clear neither clients nor health providers were adequately aware of what podiatry and foot care support is available, and where to go to obtain it.

I don't think there is enough knowledge to clients about the treatment. My understanding is that the range of clinical support to a patient is quite extensive. For example, [people think that only] toe clipping is provided as a podiatry service, where as in fact there is a whole heap of testing diagnostic procedures that should be actually implemented by podiatrists, but I understand is partly provided. (Interview 010)

Managing their feet means podiatry services – they're probably not aware that it's available to them. I only found out myself not so long ago that people with diabetes can have free podiatry checks. That [lack of knowledge] would be a barrier. It's for the Hauora to know that too, so that they can help people manage their foot care. I think that for some reason even though it's a really important aspect for Māori health the knowledge is kept from us. I found out about it by mistake when I took a lady to podiatry and she didn't have to pay for it. This is something that is not common knowledge but to me that is withholding information but I don't know who is withholding the knowledge (Interview 006)

Thus Māori are not necessarily aware of what information and services are available, may not know how to access either information or services available, and do not understand the health care system or where to find information or services. Focus group participants talked about the clear lack of followup of information. Some health care providers noted they are themselves unsure about what is or is not provided, although the people living with diabetes felt that people only knew about services if they were working as a health professional. A lot of people don't even know about things like podiatry, the knowledge of what is out there and what is available. So there is the availability of services but it is also about knowledge of availability and knowledge of access (Focus Group Participant)

When health care professionals are not aware of the full range of options different health care practitioners and providers offer, a limited menu is available to Māori patients. This person did not state that there is a limited menu of choices available, but that each person has a limited range of options that they know about.

Not knowing there's help out there especially when they go to the GP. The GP only knows to refer them to the hospital podiatrist, but in fact there are other community podiatrists, and people don't know the benefits and other choices also, just not knowing the level of support out there. Not knowing the system. There are a lot of support agencies out there to provide help. (Interview 005)

Some data also indicated opportunities to disseminate useable information to Māori can be lost when challenged to 'think differently' about their health.

... ... he highlights the tino rangatira diet, the introduction of colonisers food "white food" not good for us. "Foods are white because they are bad for us". Diabetes is essentially an introduced disease, it is a Pākehā disease and as a result of colonisation food Māori eat has changed. (Education Wānanga Notes)

The impact of colonisation on Māori eating patterns is **not** questioned in this report. However, the limitations of this form of education are evident. Such knowledge has a purpose, although does not provide strategies for implementation or change as it does not facilitate the discovery of knowledge enabling individuals, whānau and communities to find their own ways to address historical barriers to their own wellbeing. Subsequently, it is essential people who providing education are able to assist Māori to move beyond what has happened in the past, and enable them to apply a new story for themselves and whānau. In this way Māori need to be empowered to obtain and maintain wellbeing based on current knowledge, information, resources and contexts.

Yet a further barrier is created when individuals are subject to unhelpful structural processes.

## UNHELPFUL STRUCTURAL PROCESSES

The literature review (Brown and Taupua Waiora 2007) conducted for this study suggested there are currently numerous initiatives to make life easier and better for people living with diabetes and diabetes-related foot health. However, the participants in this research recounted barriers accentuated or reinforced by structural processes within the health care system. In this report the structural barriers have been summarised into six sub-categories.

- Philosophy of health care: Lack of preventive health resources
- Lack of Māori and culturally responsive providers
- Lack of sustainable funding
- Cost of foot care services
- Immobility
- Lack of service coordination

## PHILOSOPHY OF HEALTH CARE – LACK OF PREVENTIVE RESOURCES

There is a philosophical contradiction between a healthcare system designed for treatment and one designed for prevention. Current services for foot health in NZ are mainly treatment oriented, not prevention focused and funded.

Specifically for foot care one of the challenges is knowing that there is a preventative aspect to foot care. But a lot of primary care doesn't do preventive stuff very well. (Interview 004)

Genuinely preventive health services are often not readily available, and often not funded or fully funded. Services do not account for simple remedies that would assist people to avoid needing health care in the first place. Yet little research has explored the potential for the funding of preventive health care costs. The qualitative data, for example, supports the power of the lanolin emollient creams and silver colloid merino socks provided to participants in the intervention group.

These resources can also be used for treatment. As noted above, participants consistently talked about the preventive capacity of the lanolin emollient creams. In spite of their preventive benefits, many Māori who need the creams cannot afford such items, which are perceived as being 'luxuries'.

At present, the focus of the health care system is at the tertiary end, where treatments for problems such as foot ulcers are provided. For Māori, small foot problems appear to become big ones, and result in amputation. More recently, emphasis has been placed on the 'problem' of foot care and health promotion efforts aimed at educating clients about foot care in order to minimize problems.

Resources such as those mentioned above are not funded items readily available for people with diabetes on a sponsored or prescribed health scheme. How can these resources be readily obtained by those who cannot afford them? Do current policy and funding practices maintain choices that sustain the lack of preventive foot care resources for Māori?

## LACK OF MĀORI PRACTITIONERS

Nearly every participant talked about "Māori for Māori" and it was clear from conversations this was a central issue, and of importance to all participants.

It's a good collegial approach Hauora, non-Pākehā, really high skilled, Māori community. Highly skilled workforce of Māori. (Interview 003)

Participants repeatedly made it clear that despite national initiatives to increase the number of Māori health professionals (Ratima, Brown et al. 2007) there remains an inadequate availability of Māori service providers.

There aren't a lot of Māori health workers (Focus Group Participant).

Nonetheless, there were also some participants who disagreed to some extent with the idea there is a need specifically by Māori for Māori. The data demonstrated the need for an understanding when discussing Māori podiatry services, 'no one size fits all'.

In addition, the training of Māori providers was raised as a barrier, suggesting the present training processes are inadequate. This could also suggest that Māori who can train in podiatry have cultural reasons for avoiding professions that emphasise contact with unclean body parts.

Nevertheless, the data indicated a need for a greater Māori podiatry workforce. Others, as is discussed below, noted while there is an ongoing lack of Māori health care providers, it is crucial culturally responsive health care workers are available.

## LACK OF SUSTAINABLE FUNDING

Another barrier to foot health is the lack of sustainability of foot health funding, such as for podiatry clinics, preventive health resources and alternatives. Often funding for services are provided on a short-term, often ad hoc basis. Therefore services may be effective, and then be removed. This inconsistency creates distrust amongst Māori.

There is an issue for us around the continuity of care, that we can provide a service one month but not the following month, or even one year and not the following year. We need an ongoing sustainable service because that's how people learn about what is available. If it's only here for a short period of time and then it is taken away, it becomes unreliable, it affects consumers - Māori consumers' and all consumers' attitudes towards that service and its usability. (Interview 010)

A number of participants suggested even if funding were sustainably provided, the emphasis and focus of such funding must be preventive in order to make a difference in reducing the impact of chronic conditions.

Yet even when funding is reasonably consistently available, other issues create barriers for Māori, such as the cost of good foot care for individuals, and immobility.

## COSTS OF GOOD FOOT CARE

Mentioned extensively by participants, the cost is a major issue for Māori when seeking support for foot care. Cost was discussed in multiple ways including reference to topics as diverse as the cost of food and healthy diets, transport, podiatry services, specialist services and good quality foot care products.

Yes, I was referred to a dietitian. The dietitian made recommendations for foods that I can't really afford. I just stick to the stuff I can afford. (Q6 P127)

Others noted that the costs and realities of maintaining a healthy lifestyle can be quite difficult for many people.

There is the reality of people's lives, which means diabetes impacts on so many aspects of people's life - obviously - their diet and exercise. When you eat, how you eat. The kind of sense that the things that make it hard in general, if people have difficulties with feet security where they're struggling to feed their family and themselves and yet they've gotta have a diabetic diet which involves eating different food than the rest of family, or could be more expensive, and maybe not be able to be affordable so those sorts of issues all impact on how well people can manage their diabetes... .... it's really hard to get away from the fact that a lot of people struggle to make ends meet and get things

going and if you've got diabetes on top of it and of course it's associated with low energy and it compounds the problem, no matter how educated you are. (Interview 004)

A major concern raised by participants, researchers and clinical intervention providers has been the issue of the cost of transport for people with, or at risk of, diabetes-related foot pathology to foot health clinics.

Poverty, lack of money for things such as transport. (Interview 001)

Then there are the practicalities of getting to the services. Cost, transport those kinds of things. (Interview 004)

Extra costs for foot care would include the cost of obtaining the best possible socks and creams, best choice shoes, the cost of podiatry, private podiatry and specialised orthotics.

Some people simply do not have the money needed for services.

It is very difficult for people to access the podiatrist. It costs about \$45 per visit which is probably double their weekly disposable income, their surplus funds, so it's not going to happen. (Interview 013)

Financial is another barrier. If you are going private you could be seen quickly, but it's dearer than if you go through the hospital system and it could take longer. (Interview 005)

Cost of podiatry. (Key Informant Interview)

Cost of private podiatry. (Interview 004)

Then there are the costs associated with the services themselves. Cost of specialised orthotics will certainly be a barrier. (Interview 001)

The costs participants discussed are both curative and preventive. Costs are high for resources, transport, podiatry and specialized care. There are certainly known initiatives which provide assistance for transport. However, people are not always aware of these forms of assistance, or able to access them.

Properly funded podiatry care for all people with diabetes would appear to be a simple solution. Yet this solution is not always effective as one participant noted:

There are 1400 Māori [in this service]. We have sent them out direct one-on-one letters to try and capture their attention and say, "Hey, this is what you're entitled to and if you have these problems give us a ring". We've got an outreach nurse that can go out to you. We have got a whānau worker that can come with that person. A lot take it on - but you still get a lot who won't. (Interview 011)

Indeed, some Māori stated that providing free services may be a disadvantage and clients may not attend despite free and accessible services.

I don't think dependency is good for Māori. I have examples of that. We set up a completely free service at a Marae in [region]. The people were [saying], "I can't come because I've got to watch my soaps". And the thing is that those people weren't attaching any value to the service because it was something that they could drop in and out of too easily. You've got to really tread a fine line there and

this is what's hard about it, is that there are people who can't afford it and really want to be there, but there are also people who will abuse that and you can't let that happen. (Interview 0110)

This quote, however, does not acknowledge the many reasons that people may have for not attending a service. There is a lack of understanding of WHY Māori do not use a service even though it is free, The most evident consequence of this lack of understanding is to ask people why they do not attend free clinical services - and then to explore with them solutions to the answers given.

#### IMMOBILITY

The ability to access transport is given by participants as one reason Māori do not attend free services. Having money for transport is one issue, yet accessing that transport is also an issue for many with diabetes-related foot pathology, as people become increasingly immobile. Thus, over time, as people become increasingly unwell they are less able to use those transport resources available. Participants often cannot walk far enough to use public transport when it is provided. In addition, transport is provided for some services and not others.

So you've got X Hospital where you have to take whānau yet there is no transport available; within A hospital is the St John's shuttle bus, but they only provide ... It's really difficult getting to all these different places like the vascular clinic in Auckland Hospital if you're not doing too well. (Focus Group Participant)

## LACK OF SERVICE COORDINATION

Numerous participants noted the lack of service coordination is a major barrier and expressed difficulty negotiating a confusing health care system. A range of services might be available, however, participants noted each person has to navigate confusing systems, often either not knowing about services, or finding out about services rather than being informed.

#### Mixed and confusing messages about foot care

Sometimes we're told different things by the different people we're speaking to. (Focus Group Participant)

All the mixed messages out there! (Focus Group Participant)

Going to different locations for different appointments! (Focus Group Participant)

People are getting appointments all over the place. (Focus Group Participant)

Today we go for a 3 monthly follow-up for your meds, tomorrow you come in and see the podiatrist, the following day you see the nutritionist then you come back for physical activity, in one week you have appointments here in X health, then appointments in the secondary health, and then on top of that if you ended up in the secondary services to go and see the diabetes nurse you'll get another call to see the ... and then to see the dietitian, so you've got recalls to come in, then you have secondary services sending out the same korero about the same thing, then you've got about nutrition, physical activity, so after awhile I can understand why people get hoha ... (Focus Group Participant)

A lot do not know that you can get WINZ for disability support for the podiatrist. (Interview 05)

Participants talked about the need to attend many services in different areas to have different needs met. According to participants this is very difficult when you are unwell.

Sometimes the mixed messages people receive are not only confusing, but can be dangerous for clients.

My blood test is supposed to be between 6 and 9. I go over there and the doctor said it's too low; you got to go from 13 up. That's exactly what the doctor told me over there. When I come over here I got to go below that 13, from 6 - 8. When I first came here and they took my blood sugar this year it was 42. (Focus Group Participant)

#### Health professional role confusion

In addition, not every health professional is clear about what they do, compared to what is available elsewhere. Further, when there are Māori providers, participants noted other health professionals may not be aware of when and how to refer Māori clients to Māori services.

There are advocates employed to help people go along. There are some foot services that aren't podiatrist services. It is about training those people to actually work with a podiatrist to recognise what needs to go to a podiatrist. Training of Māori health workers if they're working in mirimiri; having a good relationship with Māori providers. (Interview 007)

Not only are services not coordinated, but this can also mean that certain components of health are missed.

The medical doctors and nurses [need to know] who is the appropriate person for these people to be referred to and how to refer them. (Interview 013)

Lack of co-ordination for many people - but particularly for Māori in terms of who does what aspect of care. This becomes a barrier in itself. You might have someone who picks up that you have diabetes but they might not be the same person who provides [services]. There is confusion about whose role is what. (Interview 004)

#### Overworked foot health care providers

Further to the lack of coordination, the services are often understaffed and overwhelmed.

She is so booked for one day. She only comes on a Wednesday. There are heaps of people. (Focus Group Participant)

Further, obtaining information from multiple sources can often be conflicting.

Participants noted that the community could be made more aware of podiatry services, where they are, and what they offer. It would be helpful if information about services were provided to other health professionals who could provide Māori clients with information and referral about those services.

## SUMMARY OF BARRIERS TO MAORI FOOT CARE

The above section has identified five major barriers to foot care for people with diabetes raised by the participants – stigma, unhelpful contexts, a lack of information and understanding and unhelpful structural processes. Despite recent advances in equitable treatment, Māori feel that some health professionals treat them with disrespect. This was particularly evident when health care professionals, regardless of whether or not there is any intent to be reassuring, dismiss Māori questions. Various forms of stigma compound each other. Stigma is also absorbed and internalised by Māori, and is reinforced by structural processes.

A number of barriers to foot care occur in unhelpful contexts which are related to: belief, personal, whānau, community, work and clinical contexts.

Lack of information and understanding barriers were facilitated by inappropriate information being given to Māori, including culturally and age inappropriate information. Information often lacked a credible source for Māori clients. Health care workers often provide a limited 'menu' of options for clients, as they are not always aware of the extensive range of services available.

The present health care system creates and facilitates barriers to good Māori foot care through unhelpful structural processes. These processes were described using six themes: the philosophy of health care; lack of Māori providers; lack of funding sustainability; cost of good foot care services; immobility and lack of service coordination.

However, participants also saw a new way to provide foot care, and talked about those things that would enable good Māori foot care.

## CHAPTER FOUR: ENABLERS TO MĀORI FOOT CARE

## INTRODUCTION

In the previous chapter, the barriers to good Māori foot care from the perspective of the research participants were described. In this chapter, processes that would be helpful in enabling and supporting foot care are described.

Whether physically fit or limited by physical disability, Māori have full, varied lifestyles and fulfill multiple and varied commitments - such commitments to whānau, communit(ies), employers and self. From the perspective of Māori, how are Māori with diabetes empowered to ensure that their feet remain healthy and strong so full involvement with life activities can continue - despite a diagnosis of diabetes and potential for foot pathology?

Foot health is an essential component of both diabetes and broader health-related concerns. Taking care of one's feet is part of a more holistic notion of health and wellbeing. By demonstrating what will support healthy feet, it is necessary to take into account all of a person's cultural, physical, thinking, social, spiritual and environmental situations.

What we know works with Māori - whānau-oriented, non-judgmental, readily available, understanding transport needs. If people got foot problems, chances are they may have transport problems or shoe problems. Thinking of the practicalities of the service accessibility, whether it needs to provide transport, whether or not it provides homecare, responsiveness to families, and patients, and I think that should really be built-in. Ongoing relationship development with the other people in the team, the health care team... (Interview 004)

The enablers identified by the participants were summarised into four categories:

- Health care practices that are relevant and responsive to Maori
- Create helpful contexts
- Provide enabling, focused education programmes
- Redesign structural processes

## HEALTH CARE PRACTICES THAT ARE RELEVANT AND RESPONSIVE TO MĀORI

You have to try to find that linkage between the feet and our body and the parts that are special, spiritual and tapu and also, getting into the services to be cared for... ... It's trying to weave that together. (Interview 009)

It is essential that foot care for Māori is provided according to the values and meanings of wellbeing to Māori. It is necessary to create a link between 'time honoured' and 'new' forms of foot care, and knowledge about health care and wellbeing:

I go to a Māori doctor... ... he does a different massage altogether, and I was good after that. I'm trying to get the best of both worlds here. ... I have the Pākehā medicine that he gives me and I have the Māori rongoa too. (Focus Group Participant)

Māori cultural values and practices means much more than can be discussed here. Māori culture was described as having unique qualities and Māori as having different needs that differ to other patients. What does Māori cultural values and practices mean for people with diabetes and those providing services to Māori with diabetes<sup>1</sup>?

One participant noted the essential criteria were understanding the context of Māori health, knowing the history, and maintaining consistency with the Treaty of Waitangi (Orange 1987; Kingi 2006).

It's really important that they have knowledge of the context of Māori health. They would need some public education health training, some brief course training in history and some Treaty of Waitangi training with that. (Interview 013)

Given the nature of the study questions asked, this participant did not elaborate. Nonetheless, the concept of applying Māori values and practices in foot care does raise some questions.

How would Māori foot care incorporating Māori concepts, knowledge and language be best delivered? In terms of this research project, it became evident Māori cultural values and practices can be specifically applied to the care of feet.

According to Desmond Tutu, "To be neutral in a situation of injustice is to have chosen sides already. It is to support the status quo". If our aim is to ensure what works best for Māori foot care is applied, it is no longer adequate to be neutral, nor acceptable to support the status quo about stigma-related barriers to good Māori foot care. Analysis of the data suggested more than rejection of stigma is needed.

Embedded within what they have said, participants have shown it is crucial for Māori foot health and wellbeing that care providers and patients are able to reject the status quo and move beyond the many forms of stigma described.

Participants were able to describe 'a better way' and how to create a new story of foot care in which Māori would empower themselves to write a new story of wellbeing. The story would be one in which Māori could be fully involved, active participants in their own wellbeing.

Participants showed two specific ways in which foot care can move beyond stigma. These are:

- Celebrate connection
- Ensure culturally responsive providers

<sup>&</sup>lt;sup>1</sup> Based on current available evidence, all people with diabetes are at risk of diabetes-related foot pathology

### CELEBRATE CONNECTION

If knowledge is to be shared with Māori about diabetes and foot care, and that information is to be listened to and acted on, the deliverer must first connect with the listener. This was evident in numerous ways. For instance:

Probably a person who is going to deliver it has to talk on the same level, but also have enough knowledge obviously, but be able to really relate to the type of people that they are. The delivery of it has to be from someone they can relate to, but also someone who isn't preachy, who doesn't mind sitting there and talking for a while about the whole issue around diabetes rather than just diabetes itself. So when you talk to them they feel comfortable enough to accept information without it being, "I'm telling you this is what it is". I think too much information at once is a mistake. I think that's a big mistake because people have a very short attention span, Māori and non Māori, they will only take so much in. And it's not a waste of time having that social connection first. You have the social connection first and then you bring it in. (Interview 011)

Connection was described as making people feel welcome; establishing trust; acknowledging people as individuals and members of their whānau, community with whakapapa; recognising and celebrating uniqueness as well as togetherness; and being able to talk about foot care, wellbeing and health issues (such as nutrition for instance) in a way that is understandable, and that combines current and traditional Māori knowledge.

Through connection, follow-up on knowledge and service provision would be facilitated, and Māori culture through connection would be embedded and incorporated in all components of foot care.

One instance of this is where a participant talked about her grandson massaging her feet. Such a process is culturally supported and encouraged, but also has the benefits of assisting a person with diabetes to notice and take care of their feet while at the same time strengthening the connective bond with their grandchild and educating future generations about connection.

Consequently, through connection it would be possible for foot care to move beyond stigma to active acceptance and towards cultural knowledge, respect, equality, sensitivity, awareness and understanding. Where there is connection, there is cultural content related to 'what matters', what matters about their feet for each Māori patient, and how foot care needs will be understood and acted upon.

#### ENSURE CULTURALLY RESPONSIVE HEALTHCARE PROVIDERS

Participants consistently talked about providers who 'understand' Māori. Being non-judgmental is not always enough. Extensively participants noted the value of Māori providers for Māori patients, whether for education, training or the provision of services.

Most participants stated their preferred option is that Māori establish, and provide foot care services and education for Māori. This includes, where possible, being a Māori owned, created and developed service. Others noted they would have a preference for the entire team to be Māori. Comments included that if a service were by Māori for Māori, it would be culturally attuned and sensitive to the needs of Māori, locally appropriate, person/s would feel that they and whānau were known, patients

would be less pressured than with non-Māori providers, would feel more comfortable, and information would be shared in a way that could be understood by the client and would be collaborative rather than instructive.

Māori staff: If you had a Māori diabetes service and it was Māori specialist, podiatrist, educator, it would have to be my utopia for a diabetes service. I believe that's where the potential for gain is, having our people being seen and cared for by our people. (Interview 020)

Māori people don't put the same pressures on you as Pākehā people, they make you feel more at home, more relaxed (Focus Group Participant)

I've always had this thought that if you're going to deal with Māori, you need a Māori, because I think they relate better to you. Whereas when you have a Pākehā telling you this and that... the way they're putting it over it just doesn't go down the same, to me... I get hoha... (Focus Group Participant)

There's got to be more Māori podiatrists. We can make things as culturally sensitive until the cows come home, but to be honest it's better to have brown faces and Māori people delivering care to our people. (Interview 020)

With the icing on the cake being a brown podiatrist who spoke Māori! (Interview 019)

Ideal would be a Māori person delivering it. A Māori person trained in podiatry or diabetes management and also competent in terms of Māori language and culturally competent, somebody who knows how to greet Māori patients in a way that brings them into clinic and engages them in the programme, who knows how to make Māori patients feel accepted and welcome in that kind of setting, whether its clinical or community setting. (Interview 016)

Given that we target our high needs populations – who are Māori and Pacific, lower socio economic income bracket, our service would be a Māori podiatry service. We want to have Māori podiatrists. We would want to have a good working programme, where it is clearly understood what the expectations are of those podiatrists. (Interview 010)

As noted above, a major barrier however is a current shortage of Māori foot care providers. Given this shortage, one participant's recommendations to overcome this barrier were:

We would want to have a recruitment and support strategy that ensures that we have a continuous flow of new recruits and people being educated by current experienced podiatrists. (Interview 010)

In the mean time, participants acknowledged there would not always be a Māori service provider available and currently an extensive Māori podiatry workforce is lacking.

Because a Māori health workforce is not readily or extensively available (Taupua Waiora 2006), participants realised a compromise is often necessary, and the best possible alternative was posed in the interviews.

It has to do with a kind of partnership rather than, "This is what you should do" approach. A lot of that has to do with understanding the Tapa Wha<sup>2</sup> model which has to do with treating the patient holistically and really knowing what's going on with the patient and their world. (Interview 014)

Make sure that the person, who delivers the podiatry education and support, knows our people, can react to them, can relate to them, and knows what it means to support them. Ensure that a good relationship is established with them or establish a relationship with others that you think could benefit or could help support our people. Just networking... Someone to deliver the podiatry service, probably a podiatrist themselves, but there is only a few, so they can work in with the community podiatrist to contract or something like that or deliver that part of it to ensure that it is there for our Māori - and that includes anything else that comes with being a Māori service. The cultural side of things - make sure that whatever they're [health professionals] doing with their [Māori] feet is appropriate. ... Make them feel welcome, at ease. (Interview 005)

When service providers worked carefully alongside Māori providers and made sure services were appropriate for clients, they were ensuring culturally responsive practice occurred. Further, stigma continues to occur in health care contexts, highlighting the need for urgent training in cultural responsiveness for all health care workers - undergraduate and postgraduate and those already in the system.

Durie (2001) notes it is important to recognise ethnic culture is one of many cultural affiliations (for example age, weight, or economic situation). Developing cultural responsiveness helps to ensure a better understanding of members of other cultures, and would provide health care workers with additional knowledge and information necessary for providing improved health care.

According to the data, when health care providers have knowledge and understanding of Māori ways, they are better prepared with the background needed in order to ensure the provision of effective services, helpful knowledge, and information and skills to make a difference in the foot of Māori health. Cultural responsiveness would also result in services creating more helpful contexts for better foot care.

## CREATE HELPFUL CONTEXTS

Unhelpful contexts are major barriers to self-determination in good foot care. Such contexts involve negative ways of thinking about self, lack of acceptance of the condition, as well as whānau, community, work and professional contexts that create barriers. How did participants say that these issues could be turned around to create helpful situations? Helpful contexts were identified in three main ways:

- New ways of thinking: Self-engagement
- Whānau and community engagement
- Establish clinical connections

## NEW WAYS OF THINKING: SELF ENGAGEMENT

In self management the actual raising of awareness of the important fact is that once you've got diabetes, you cannot reverse it but you can control the symptoms by exercise, food and diet. I think that over the years we've just accepted it that once you've got diabetes that's sort of it. So there are programmes around, so just to self manage now and actually, I hate this word, empower people too., You can't empower people if they don't know that they can get some sort of control about actually taking control. (Interview 007)

Acceptance of a diagnosis and an understanding of the impact of diabetes on all of the body, including one's feet, is essential. Quite often in the qualitative data, people noted that an important component of getting help is awareness of the condition and engagement with what is happening.

For many, the diagnosis is difficult to accept. Participants suggested or indicated, sometimes indirectly, accepting that one has diabetes will result in people discovering ways to best manage its presence in their lives.

This is what [participant] is excited about - she's getting out doing something for her - and she's getting professional help. ... That's why [participant] is excited because when she comes here, she gets away from home and has time to look after herself. (Education Wānanga Notes)

One participant noted that the key to mind body disconnection was for people to 'take ownership' of their condition, which requires reflection, acceptance and self engagement:

There needs to be some kind of ownership from that person or to take on board and say, "Yes I have got diabetes". ... ... Until people can come to say, "I've got diabetes, this is what's happening to me", and take responsibility and they identify what needs to happen and we facilitate that for them - for that to happen. They've got to take ownership of it, they've got to express their needs and we can support and help people with that be it education or whatever. I think that it's almost like, "It's no big deal to me". So there needs to be some real serious stuff going on, people need to snap out of all that and say, "Look I've got diabetes, it means something to me" because it is life threatening, it really ravages the body. There has to be some ownership around it. (Interview 009)

Another context which is often personal to some extent is medication management. Surprisingly, very little attention was paid to the management of medication in this study. Although not talked about specifically by participants, medication effectively managed, whether by self or by another, is an important component of self-engagement and creates a helpful personal context in which all components of good foot care can be facilitated.

Russell and Browne (Russell 2005; Russell and Browne 2005) talked about mindfulness as an essential start to accepting a diagnosis with a chronic disease and moving forward to action.

Self-engagement demonstrates acceptance of a diagnosis and willingness to take some responsibility for one's own healthcare. Self-engagement can result in the development of a personal plan that is helpful to manage foot and health care.

The Māori providers here now work with plans, each person has to have a health plan that's part and parcel of that. (Interview 007)

A personal plan, according to Russell and Browne (Russell and Browne 2005) is developed personally by the person with the condition which may or may not be in collaboration with a health professional. The personal plan not only identifies triggers and warning signs, but also makes clear what the person will do to avoid remission, how they will respond when they experience a trigger or warning sign, how they will ask, and what sort of help they will ask for. Plans also acknowledge that individuals are part of a much wider context and assist people to decide who they will ask for help when they need it, and how they would like that assistance to look.

## WHĀNAU AND COMMUNITY ENGAGEMENT

According to the participants in this study, it is crucial to involve whanau in health care.

Q: So having the whole whānau involved?

Yes, so that you've got a support system. It's not that they'd want to check up on you, it's just to help you.

Durie (Durie 2009b) highlighted the imperative to create empowered whānau who are champions for health. At a recent presentation, Mason Durie said:

The best prospects for Māori health and wellbeing in the future will lie with whānau (Durie 2009b).

A participant talks about implementing the whare tapa wha model in Māori health (see Glossary of Terms). Durie talked about the notion of putting whānau at the centre of health care and that whānau can become agents for health. From his perspective, Māori models of health are holistic and the principles of such models include family and community or whānau, physical or tinana, spiritual or wairua and mental and emotional aspects of wellbeing – hinengaro (Durie 1998b).

Participants who had received the intervention were asked about involving their whānau in their foot health. They indicated they had shared the study with mother and brother (2), sister/s (2), mokopuna (grandchild/ren) (1), wife/husband/partner (3), whānau (1), whānau in other countries with diabetes (1), niece and neighbours (1). Seventeen participants had not shared information about the study with their whānau. One participant said they might do that now, another said the whānau were not interested or that they had not given feedback on the study.

The participants who were interested in sharing the study with their whānau frequently said it was important to do so, and that sharing with whānau provided benefits.

Yes, I did share this study with my whānau. It has certainly brought about a greater awareness of diabetes to my whānau. Like changing one's habits that lead to good health. (Q6 data 228)

The consequence of sharing this study with whānau were people with diabetes were able to develop various forms of support.

They bring the recipes but we need to cook it ourselves. We have all these things but we don't actually do it because you gotta cook it, unless you can see how it's done. My dad was diagnosed when he was in his 40's, one of the things he found was having good support. Even when he was alive he was a good support for me, I used to say to him "how are your shivers today pop?" And he'd say, "How about you?" What my mum used to do was prepare meals for my dad and set breakfast

and lunch at these times. When we had them we never got hungry. You have a look at our sugar levels, it was none. We had soup for lunch and she introduced us to brown bread. (Focus Group Participant)

This increased self-engagement through greater awareness, and included reminders to check their feet, monitoring by whānau, being supportive, and proposing options for whānau members that might be more suitable to someone living with diabetes. For some, there was a sense of shared load and of being cared about. Whānau members also developed knowledge and awareness of the impact of diabetes and information they may need one day.

The study contributes to whānau awareness. (Q6 data 212)

I have 2 other sisters who also have diabetes. The korero is about diabetes care in relation to helping the whānau as a whole, especially the tamariki. (Q6 data 214)

My whānau and I realise that the whānau needs to be involved in mahi that has physical content... (Q6 data 214)

Yes, I have indeed shared this study with my whānau. Many of my whānau members have diabetes and are now doing their own little bit of research. This project has motivated my whānau to think deeper about the effects of diabetes. (Q6 data 225)

Crucially, some talked about how whānau found the study as an opportunity to learn about diabetes, to learn what they, as a whānau, can do about diabetes, and provide support for members who have diabetes. Further, it assisted people who are at-risk of developing diabetes to be more aware of how they can prevent it. Additionally, positive whānau histories were being created. For example:

Yes I did share this study with my niece, she was interested in the effects of diabetes and how it may affect her and others. (Q6 data 238)

Whānau see study in a positive light. What can we as whānau learn from this study? Q6 data 223

Health professionals also talked about the importance of whanau involvement.

I wouldn't just get the person with diabetes. I think it has to be broader than that. I'd do it from a whānau base. I guess it varies in each individual group, whether I'd initially start with the immediate whānau or the aunties and uncles, or if you're in a rural area you could probably get more tribal more iwi buy in. I'd probably do programmes around the whole thing. All the research is showing that exercise and food can make a difference. I've worked with the whānau even if they haven't got diabetes because of the hereditary link - because of the way it has run in families. But it's not genetic it's actually lifestyle that's leading to diabetes. I'd do the whole thing right from the prevention programmes along to these sort of whānau base programmes, and perhaps the individual and personal stuff with the foot care. (for instance) I don't think my nanny would like her feet being looked at by everybody - that sort of things is still personal(!) (Interview 007)

Having a supportive group of people all kind of working on how to manage their diabetes together in a kind of a whānaungatanga way... But also the spinoff is that those people would be taking that information home and applying it to rest of their families. Māori understand what Māori are going to be

looking for, so they know some of the challenges for them in helping their families and help adapt *Māori* to lifestyle changes like that. (Interview 004)

Whānau can also be supported to provide an encouraging environment.

When you're talking about the need to provide educational information, not just for ourselves as the people with diabetes, but for the wider whānau in the household so that the whole environment becomes supportive (Focus Group Participant)

It would be nice to circulate a pamphlet with the information to everyone in the household, so it reinforces what you are doing (Focus Group Participant)

One of the things that has come out of the programme is that not only do the individuals with problems need the reinforcement and re-education and encouragement but the whānau need it as well (Interview 014)

According to these reports, whānau engagement, if done properly, would be much more than simply inclusion of a significant other in a medical interview.

The benefit of family involvement has long been known, both for themselves and for the person with a diagnosed health condition. Bailey, Yu and Rayfield (Bailey, Yu et al. 1985) for instance, indicated there are many instances where conditions were first recognised by a relative or health care staff rather than by the person themselves (Macfarlane and Jeffcoate 1997; Apelqvist 2000). Given the level of incapacity and immobility that may be associated with diabetes, there are many who would be unable to assess their own feet. Therefore it is important to establish the benefit of involving family members in checking and monitoring when the person cannot do it themselves, or does not understand the signs (Lavery, Higgins et al. 2007).

Creative involvement of whānau and community were explored and implemented in some Māori health contexts:

A worker down here ... is running a lifestyle intervention programme and they did things like take people to the supermarket and help them read the back of the packet stuff like that to make them understand, took them shopping, did cooking, went to the swimming pool, a whole lot of stuff that was supportive, that worked really well with the community down here. (Interview 004)

However, although participants frequently call for whānau engagement, as do others in health care, little is known about how this can best be done on a practical level, or how it would be funded and supported. Given current ways in which health care is provided, without funding, how can health professionals be motivated to commit extensive hours and energy into ensuring whānau and community can assist people with diabetes in an informed manner in the right way and at the right time?

There are as many questions as answers raised in the concept of whānau and community involvement. There is minimal knowledge about how, when and why to engage whānau and community members in the most helpful ways to support people with diabetes to maintain healthy feet.

For instance, who are the whānau and who is the community for people who live with diabetes? How many people are, could, or should be involved in education and service provision? What does each person with diabetes want in terms of whānau and community involvement? How do historical whānau and community actions and activities impact on the actions and behavior of Māori with diabetes? When, who, and how should whānau and community be asked to help? How can a person with diabetes ask for assistance in a way that is right for themselves as well as whānau and/or community members? How can whānau/community offer to assist people with diabetes in a way that is empowering and not patronizing?

Broader questions also emerge. First, although 'family involvement' is readily talked about and discussed, minimal attention given to the budgeting of health services to provide assistance or education that is specific to any whānau or community group, and especially extending this beyond one or two people attending medical interviews.

In addition, creating helpful whānau and community contexts would address such whānau and community issues related to the pressures of daily life, such as moko (grandchild) management, costs and transport. How can such issues be creatively managed?

## ESTABLISH CLINICAL CONNECTIONS

Participants described the type of relationship they wanted and that would improve Māori relationship with practitioners. They noted it is important to feel connected and understood. Participants talked about needing to be 'visible' to their practitioners, and for continuity of care to enable the development of meaningful and connected relationships.

For some, seeing health professionals as someone to 'report to' made a difference.

And it's just having that nurse here that I have to report to make a big difference for me too. (Focus Group Participant)

There was an implied understanding, both in the above quote and the data overall, that when Māori know their health provider (whether that is a doctor, nurse, podiatrist or other) they would feel more valued, connected and understood. Through this sense of greater connection, it is implied, therefore, they would be more likely to be forthcoming about their needs, and the health provider would have a more global view of their individual foot care needs.

## PROVIDE ENABLING, FOCUSED EDUCATION PROGRAMMES

## Information is power. Māori patients need to have that information in a way which works for them. Interview 016

The following participants summed up the repeated requests for knowledge and information by participants:

Knowledge is probably the best, that's probably the primary. You don't have the knowledge - you don't know what the hell you're doing - and you don't feel confident in doing it so you just leave it alone and don't do it. End of story. (Interview 011)

Perhaps rather than putting the message across at an individual level, having en masse stuff is a good way in which our people learn - wānanga. Why try to convince all these individual patients about the importance of podiatry as opposed to the whole group, which I think, has the benefits of collective thoughts and support. There's a lot of possibility of going away from the Pākehā model of just targeting the person in front of you as opposed to looking at a more communal approach to how you educate. Still focused or targeted to the education for diabetics but in a collective setting......We've got to make sure we have a service that's appropriate to our whānau. Interview 020

Some discussion in one focus group, however, highlighted that it is important to be focused when providing education:

Target feet, stick to information on that. Cracking skin – not just pumice – how to get rid of cracking.

Building Māori relevant education programmes requires the provision of enabling, foot care focused information people need in the way that they can absorb it.

Focus group participants reiterated that they "want a place to go to learn about diabetes".

Participants proposed directions and suggestions for any future wananga or education programme. Such suggestions discussed content that covered a wide range. This content ranged from finding out what socks and shoes to wear, the best creams to use, what tests and medications mean, what diabetes does to their bodies, nutrition management; to how can Maori and health care providers talk more meaningfully and usefully.

If education for Māori is to be consistent with the Treaty of Waitangi (Waitangi Tribunal) (as noted above) then it is essential to explore who will provide information and how it will be provided. In order for an education programme to be appropriate, participants talked about the need for 'crucial information', and the need for multiple information sources to meet different information needs.

Enabling and focused education was categorized in 4 ways:

- Crucial information: what I need to know is the facts!
- Māori and age relevant content
- Useable in a Māori way
- Locally appropriate approaches
- Multiple information sources
- Appropriate venues and times for learning

#### CRUCIAL INFORMATION: "WHAT I WANT TO KNOW IS THE FACTS!"

Having established a connection ensured cultural content and culturally responsive providers. It is also essential to provide information that matters to patients in a way that will be understood and is achievable.

Not only do Māori need their questions answered, but they need specific answers. Patients require information that is meaningful to them, and adequately answers their questions without trivialising those questions. For participants it is clear knowledge alone is not enough.

What I want to know is the facts [(Focus Group Participant)]

When do you take my blood? I want to know why you are, what is it being tested for etc... and blood pressure. Learning about having high blood pressure - the effect it has on your kidneys. They actually don't talk to you about that - they might - but it is not always guaranteed. (Focus Group Participant)

Why I'm saying that is, how many people know why under their feet is flat... ... Or why is it so important to have the skin under your feet so moist? Or what is happening with the grades of their joints, or pressure points. They need to know why their skin is cracking and how they get rid of it, not just with pumice. Are they going to use cotton buds or something [else] to put creams on? Show them with their hands - it's easier to understand and it works faster. Stuff between their toes and things they need to know like this. Show them this. That's some information anyway. That's good stuff. It's education. (Focus Group Participant)

When people come to see me, in terms of podiatry, you can sit there because you're not looking down their throat like a dentist, you can talk to them and they can talk back so whatever you say to them should be aimed at information but not overload. (Interview 011)

Focus group participants and an interviewee made it clear the information about diabetes takes repetition to absorb, and many repetitions and explanations may be required in order to understand information and fully grasp how it can be applied.

I find if you reinforce and reinforce over and over it eventually does, people will eventually take care of their feet

Q: Reinforcing and reiterating by whom?

A: Well people like myself as the disease state management nurse or diabetes nurse educator... (Interview 002)

Māori need challenges and to be 'stretched' in their thinking too.

Culturally competent also means they can challenge Māori patients out of their comfort zone. They want to get people out of their comfort zone and then push them along and stretch them and challenge them all in a way which is in an acceptable context for Māori patients. (Interview 016)

Health professionals' 'busy-ness' was mentioned as a significant barrier to information sharing. Providing crucial information requires the time is allocated and organised as part of health professional care provision.

When Māori are admitted to hospital or for any services, it is necessary to ensure crucial information is required to disband the many fears, and to provide information about what will happen and when. Fears, such as those mentioned earlier, of the amputation of feet or of the 'big brother' nature of health remain important. Thus information is required not just about the disease process itself, but also to alleviate fear and to empower Māori to make realities manageable.

When foot care or health knowledge is obtained, the person must first accept knowledge as legitimate, useful and relevant to the person's daily life. Thus in addition to acceptance of understandable and sensitively challenging knowledge, it is crucial that patients be able to put it into action.

## ENSURE MĀORI AND AGE RELEVANT CONTENT

A major barrier to absorption of information was the lack of relevance to Māori, requiring 'cultural content'. Throughout the study the true meaning of this statement was taken as a given. Further, part of the value placed on having 'Māori or culturally aware providers is is underpinned by an assumption that being Māori means the provider will automatically be attuned to the provision of Māori content, and the capacity to automatically know and understand talk about what matters to Māori clients.

The implementation of cultural values and practices ensures cultural content in all diabetes-related practices. Providers should be aware of Māori life and be able to include Māori examples and explanations, references and information: Pictures of patients should include Māori; information delivered in te reo as well as English; food discussed, illustrated and pictured including Māori traditional foods; practices described would include Māori practices. Through such content it is assumed that Māori patients would be better able to identify with the answers they are given and the information explained. Such content is embodied by discussions of whānau and community, and of Māori traditional foods, practices, and ways of being.

## USE LOCALLY APPROPRIATE AND RELEVANT APPROACHES

# They would be local and onsite, it would be with an appropriate provider who was either known or very user-friendly. (Interview 019)

Each local context requires a unique approach. Māori are diverse. Difficulties arise when services attempt to provide a standardised model without flexibility according to what is available and possible in the local area. In order to ensure flexible local approaches are used in the provision of services and education, it is important to ask the people in each context what is needed.

How it functions would be guided by what is the way to make it most accessible. Understandable to the community to which it is providing a service. So it might be something quite different happens. In some respects it's how that it needs to be responsive to the needs of Māori with diabetes in that community... [Services and education] need to be reality based. There needs to be really, really good high quality information understandable to people. [Education should] feed into service. (Interview 004)

The literature review also indicated inadequate knowledge about local contexts for Māori. For example, services may differ significantly between locations within New Zealand, and people can obtain certain services free in one place but not another. It is important for equity to be established in what is available, an exploration undertaken of what is available, what is needed, and how it can best be provided and supported. Ensuring approaches to education are locally appropriate will facilitate helpful contexts.

# You really have to be able to impart that knowledge you have and be able to get them to understand it and implement it. (Interview 011)

There is a need to talk about how information is provided in a way people can act on, and determine what people need so they can act on what they have learnt. Literature abounds about how people know what it is they should do, but for many reasons do not do it. One of those reasons is said to be

the lack of knowledge about what to do to act on information they have. Participants put forward some strategies necessary for ensuring information sharing results in acting on that knowledge. For Māori, again connection is an important key, and as the following participants indicated:

There would be a real sharing of information rather than a list of instructions about what to do. (Interview 019)

Further to this information, it may be useful to know who can help, who can you turn to in crisis etc. What's good about him is that he tells you what's wrong and he gives you this or that to fix it, or he sends you to the hospital. The services are really good. (Interview 013)

In addition, membership and awareness of group programmes is helpful to some people. Making health education fun for the recipient is also at times valuable, especially when talking about education programmes.

[Our] programme here is a lot of fun. People are going shopping and doing stuff together and could easily build healthy feet. It doesn't feel like you are just trying to prevent the nasty inevitable, but they're actually having a healthy lifestyle, which includes doing these things. (Interview 004)

Checking person can then apply what they know in realistic ways in their daily lives is also a professional responsibility. Therefore it is important time is organised as part of each person's personal plan.

Factual and useable knowledge, discovery, relevance, appropriateness and challenge are all obtained through multiple sources.

#### MULTIPLE INFORMATION SOURCES

People hungry for knowledge about foot health may have a range of different sources for knowledge, information and diabetes services. Peers, books, traditional healers, internet, the media and recipes from other cultures are only some of the many forms of information that were described.

I'm getting mine from my relations, from my friends. That's got nothing to do with this health sector. (Focus Group Participant)

I have the Pakeha medicine that [the doctor] gives me and I have the Māori rongoa too. (Focus Group Participant)

The other thing I think that Māori have less acceptance of western medicine than western people, perhaps a degree of skepticism and maybe a greater acceptance of other forms of healthcare, or alternatives. (Interview 014)

Pharmacies were considered an excellent source of information about diabetes, although this needed to be integrated and coordinated with the information given by other sources. Groups, peers and books or pamphlets and other written forms of information are important sources of information and support:

Being in a motivating group like this, that would motivate me. I would like to have their phone numbers so I could say, "I'm having this for breakfast this morning", "Oh I just had that, I would love that". That

would keep me on the straight and narrow and I'm hearing a lot of nice feedback. That's what I'd like, information from a group like this...... What I'd like is interaction from us and we could make that tree grow. If there's somebody else that's having problems with their diabetes I want to be there because I've changed my eating habits. I'm doing a lot of reading in there and it's mainly eating Asian kai or Chinese kai with the herbs that they cook. (Focus Group Participant)

Q: Where did you learn how to look after yourself?

A: Books and meetings. Meetings with dietitians.

Q: So do you find the chemist helpful?

A: Yes. I don't know if all chemists are the same. If I get a prescription for something I've got from the doctor, he gives you all the right information. He's wonderful. Most chemists are like that if you ask them. If you do ask them what your medication is for, they normally give you feedback. Someone who knows what they're talking about.

I actually cheat, when my doctor tells me what this is, I go back to the pharmacist and ask, what is this for? She tells me and I write it down so I remember. My chemist and my doctor. Someone you have a relationship and trust with (Focus Group Participant)

Māori seek support from other Māori and many non-professionals. Some participants pointed out the benefits of support from non-health professionals and peers.

He has had information before - but the difference was being with others with diabetes. (Education Wānanga Notes)

If there was a like-minded 'someone' who is Māori, who has had experience in progressing and learning by example, someone they can relate to in that respect, someone who has been through the same thing, e.g. Māori from a similar socioeconomic background, so they can say, "Hey this is kind of like me". Rather than just being told look I did this if you do this this won't happen. If you had an old couple that did this and it's much better now; so that could be a positive thing as to whether in regards to te reo it will differ depends on who you're presenting too. It depends on whether you are presenting to rural or urban Māori. It would be great if someone could speak te reo, even if it's not the main person educating the group. (Interview 001)

Māori would very much appreciate having Māori specific resources, that are again constructively and positively not being scared to death, having people telling their positive stories how to manage their feet knowing when to seek help and all of those kinds of things, done in a way which is really helpful. (Interview 004)

Some participants suggested that groups of clients who receive education also need to be Māori and stated that they would feel more comfortable in an information group of Māori.

[I would prefer] a Māori group. This is the beginning and I'd like it to grow. It's awhi one another and this is what we're needing, more support. Awhi and support, that's for me. (Focus Group Participant)

That's what I'd like, information from a group like this. (Focus Group Participant)
Thus, it is important to recognise no one size fits all, and that Māori collect information, knowledge and strategies about diabetes and foot health from multiple sources. Although it was noted information from multiple sources can be confusing and contradictory. Also important is ensuring information is consistent across sources. It is also important to make sure education programmes are provided in the most appropriate venues at the most suitable times.

#### APPROPRIATE VENUES AND TIMES

How should information and education be shared with Māori in meaningful ways? According to the following participant, it is crucial to consider the way and when knowledge is best delivered.

To sit in a lecture theatre type style, no, it would never work, wouldn't get them there anyway. Whānau worker, in the kitchen, cup of tea, talking about the general things and trying to relate is a lot better than even getting them into the surgery. It should be always backed up by the health professional. (Interview 011)

Participants recommended that the timing of education group events is important. A suitable time for interventions or education must be found within the group. Although ideal for workers, evenings and weekends may not be ideal for older people who found the wānanga to be held at the wrong time as they were too cold, too tired, and unable to concentrate the whole time with low blood sugars at that time of day.

Frequently, the data indicated the need for outreach podiatry held in local accessible places, or people's own homes.

Why not have a mobile clinic that you can access to the people. (Focus Group Participant)

There are people out there that need mobile services. (Focus Group Participant)

If they're still doing the physiotherapy up there, it is still the same - why can't they do it for diabetes too up there. You got the best facilities available, the best tutors. People used to love going there because we're sitting there talking, getting to know the tutors. I think it's a magic place; the only problem is getting parking sometimes. (Focus Group Participant)

Innovative, creative or simply commonsense strategies can be put into place. For example, in some areas of NZ mobile outreach diabetes buses operate, where foot care is incorporated and preventive health is provided.

What people have a right to have access to and all of those things should be part of [education to people with diabetes]. Interview 004

Providing enabling education programmes, would be focused on information that is crucial, rather than the dismissive uninformative responses talked about in Chapter Three. The type of focused education to enable Māori to take better care of their feet would provide information about tests, and how to prevent problems arising, how to recognise when something is going wrong, and when and how to act. Such information must be provided in a way informed by Māori values and practices so it is useable to Māori and relevant to a person's needs, age, culture and local/whānau contexts. In addition, when establishing education programmes it is crucial facilitators take into account venues, times and other components important to participants, such as the provision of diabetic foods.

# REDESIGN STRUCTURAL PROCESSES

The provision of high quality foot care to Māori requires thinking about health care in new ways. Such thinking might require the health system be 'redesigned'. An emphasis, on more preventive than curative health care makes preventive resources more readily available. Teams of practitioners would work together in an integrated way across the disciplines, with sustainable funding.

The themes which described how structural processes could be redesigned were:

- Preventive philosophy of health
- Sustainable funding
- 'The whole package'
- Coordinated and integrated services
- AAA Accessible, Available, and Affordable
- Quality assured services and education programmes
- Media: making it known
- Creative thinking in foot care

## PREVENTIVE PHILOSOPHY OF HEALTH CARE

Some things are free, and make a significant impact on health. For instance:

Walking too – sometimes feet make you hobble but walking helps decrease 'hobble'. Walking, take a long walk. (Focus Group Participant)(s)

This participant's comment provides a reminder that the best health resources are often not in a medical clinic, but part of daily life. However, it also highlights the need to provide good preventive information to clients.

A major barrier to the uptake of foot health is the lack of preventive health resources. Qualitative data indicated the lanolin emollient cream and merino silver colloidal wool socks that may reduce foot-specific pathology among Māori living with diabetes are well beyond the budget of many who need them (see above). However, such socks and creams are not distributed readily to Māori with diabetes as a preventive measure and are not available on a government-funded subsidy scheme. If preventive health resources were more readily available, it is possible health care needs, and subsequently costs, would decrease.

But at the end of the day, that foot problem does not have enough education of continual korero kanohi ki te kanohi on how best they can manage that. Yes, we talk about diabetes and complications. We need more education in the prevention, we need more education about to turoro, if we do this then it will prevent this. I think that kanohi ki te kanohi with the right korero. (Interview 015)

It is time to move beyond the rhetoric of treatment and cure and take preventive action. It is well known that the focus and primary purpose of health care is 'illness care', rather than promoting wellbeing. According to the data collected for this study, it is no longer a question of, "How can we help people who have diabetes-related foot pathology?" Rather, the question that is necessary is "How can we ensure that we prevent diabetes-related foot pathology **before** it occurs?" The provision of preventive health resources for people with diabetes is more than just medication, but require action at the policy level to ensure availability to all people with diabetes.

The above information raises the question: How best can Māori be supported to obtain the preventive health resources needed, such as appropriate education, and other preventive health resources, before the symptoms of pathology occur?

## THE WHOLE PACKAGE

The 'whole package' is one participant's words (Interview 004) for creating a service in which all parts work together in a supportive, coordinated integrated and multidisciplinary way, which includes non-professionals (e.g. whānau), in order to provide the best possible support for foot care for Māori. The whole package would include sustainable funding, available, accessible and affordable services and education that are quality assured and meaningful to Māori.

Bringing it home. That would be my number one thing is to bring it home. Involve the whole package - not just a podiatry programme, [and including] that ongoing relationship development with the other people in the team, the health care team. (Interview 004)

I felt there should have been a place where I could have gone to learn about diabetes and learn everything. You've come just to focus on the feet, there's the nutrition, there's the heart disease, there's the kidney problems, there's eye problems, but everyone's doing things in silo. You could bring the whole kaupapa together, so no I'm not just worried about my nutrition, there are all these other things I need to be aware of. (Focus Group Participant)

A good collegial team approach. I'm talking about the specialist skills. So that it's a team approach that it looks at the characteristics of your locality. All different, it's the characteristics of your community. It's a good collegial approach Māori Hauora, non-Pākehā, really high skilled Māori community highly skilled workforce of Māori. It's so bad for Māori – we should be more skilled in this area as Polynesians. (Interview 003)

Other participants explained that it was crucial to ensure services are coordinated if they are to be effective.

#### COORDINATED AND INTEGRATED SERVICES

Participants discussed the need for services that are delivered in silos, and involve a range of health professionals who work together in an integrated, coordinated way to provide comprehensive care for all a person's needs - physical, mental, spiritual and social. In addition, a service that provides genuinely holistic care will ensure whānau, allied and complimentary community services are also available.

There would have to be a lot of liaising with general practices, secondary, tertiary care, for one thing so there was some referral base set up. (Interview 001)

A one stop shop interestingly enough. It won't just be podiatry. I think Māori appreciate having any health practitioner who's an advocate for the whole system. So if you came to this broader sense of a diabetes care clinic for Māori patients, it maybe because you came to this clinic because of your podiatrist, but via your podiatrist you're hooking up with somebody who is going to help you look after other aspects of your care and take an interest if it's to do with your housing, your benefit or your job or talking to your kids about what's going on. (Interview 016)

Setting the groundwork to have a good service is really important for it to be successful. ... ...we've got some quite good models amongst Māori health providers in terms of what is working and what is accessible, but with diabetes, being part of a coordinated picture is really important. (Interview 004)

A podiatry service - coordinated with other services. And the tricky thing is that if you have not got all the other services that are highly functional then you could end up with a really fabulous podiatry service but the other services do not, so it has to be well linked in and coordinated with part of a healthy overall diabetes services. It sounds idealistic it would be a hard thing to be an excellent podiatry service in amongst a crap service. Interview 004

Their GP not knowing - or not really caring - that there is a really amazing Māori podiatry service up the road. They may feel threatened by it, and so I think, "Will that relationship work between the people that provide the service?" It really is important in order to make it accessible. You could have the best service in the world, the referrers or the people who they end up having to go to, the diabetes nurse educators feel threatened by the Māori services, I've seen this happen all over the country where great Māori provider services are setup - but the GPs or the Primary care services don't really know about them or are threatened by them so don't refer to them, ... ...all of that needs to be sorted out, to make it a safe and coordinated thing where people feel really good that they can go there, and they're told about it by whoever is managing their diabetes otherwise you could end up with an isolated standalone service. (Interview 004)

## AAA – AVAILABLE, ACCESSIBLE, AFFORDABLE

The question as to how much should be paid, what is too expensive, and how to charge for a podiatry service was debated by participants.

Easy access, has to be affordable but also has to be appreciated otherwise if you don't stick a value to something, people abuse it. (Interview 011)

It would have to be affordable, so free is a really good place to start. Affordable, because I mean if you're not diabetic you'd pay the \$10, if you've got long term health care \$26 or something like that. If you've got no health problems, definitely affordable, accessible bringing the service to them. (Interview 012)

Others disagree with the notion of free services, and believe that this may decrease rather than increase attendance:

The price of the treatment. I don't necessarily believe that it should be free, in fact I don't. I don't think dependency is good for Māori, and I have examples of that in that we set up a completely free service at a Marae... .... The people were like, "I can't come because I've got to watch my soaps". And the thing is those people weren't attaching any value to the service because it was something that they could drop in and out of too easily. You've got to really tread a fine line there. This is what's hard about it, is that there are people who can't afford it and really want to be there, but there are also people who will abuse that and you can't let that happen. So financially, whether it's going to be completely free, a koha, or full price. That's something that you'll have to work out with the population you're dealing with. (Interview 011)

#### SUSTAINABLE FUNDING

Participants talked about the need for funding is provided in a sustainable manner for programmes to reduce the impact of foot disease.

The [diabetes programme] here was setup as part of research and so it was really good, but as soon as the researchers went, they said, "We can't justify funding this". A really good service goes out the window, and you end up with people that have a real need for it, but it is not being provided. So sustainability! How do you set up a service that's maintained and sustained and funded and resourced and in there for the long haul, as opposed to being there for two years and then disappearing because the funding has gone and then you leave all these people in the lurch who have gotten used to a particular service. Once you have got a good service, the commitment is really about how you sustain it in the long term. (Interview 004)

There is an issue for us around the continuity of care, that we can provide a service one month but not the following month, or even one year and not the following year, we need an ongoing sustainable service because that's how people learn about the buckets of availability. If it's only here for a short period of time and then it is taken away, it becomes unreliable; it affects consumers Māori consumers and all consumers' attitudes towards that service and its usability. (Interview 010)

If they see Māori providers falling down all over the place it is not because they're not providing a good service, but because that funding and resourcing issue is insecure. And someone new comes along at the funding arm of things and next minute they're saying we only fund you to do this and not that. Interview 004

Providing services to facilitate healthy feet, funded by the health system needs to be affordable. Costs apply to individuals, and this research demonstrates clearly that availability, affordability and transport to are crucial for their usage, yet it remain contentious issues.

#### QUALITY ASSURANCE

The quality of a service is based on a number of fundamental processes, two raised by participants. First, one person noted that the quality of a service usually improves according to the feedback it receives.

Like any service, it takes it a while to get it just right. I think one of the things is quality. Continuous quality improvement - staff should be aware of any service. We might use a whole lot of research to

design a service, but once you get it up and running, you might end up [re-]thinking, based on feedback from people. There should be ongoing feedback into the service, things not being set in concrete. Then there is a culture of ongoing improvement and responsiveness to families, and patients. That should really be built into it. (Interview 004)

Some commented that enhancing the quality of any service required trained and skilled professionals.

[There should be] a competent podiatrist with good communication skills who could come to the clinic on a specific day each month and check the [people with] diabetics

Wherever possible high quality high calibre staff. (Interview 008)

I guess that if we want to do the quality stuff, then we have to bend the rules a bit to cater for the needs. Perhaps mobility can be serviced with the needs for foot care, specifically for those with diabetes. So you may have one every three months perhaps of access to rural areas. I have to be thinking in terms of the hardest factors that stops my people from accessing good quality care, so I'm talking about the real hard stuff that prevents that, and when we do get to the specialist we usually have to have both feet amputated, I'm trying to avoid that before it gets there. (Interview 015)

According to one participant, it is very important that health professionals are not only skilled, but accountable for their practice. For instance, one participant noted when she became involved with this study she had the *right* to request quality care. At the wānanga, she praised the presentation given by a doctor, and felt encouraged to hold her G.P more accountable for the care provided (wānanga participant).

Providing a quality service for Māori is more than setting up and funding a service. Quality is represented in many ways, requiring continuous feedback, responsiveness, flexibility to provide services in novel ways (such as through mobile services), local relevance and professional accountability for practice. In addition, improved quality service occurs when there is integration of services.

#### MEDIA

Two participants suggested advertising could be used to make people more aware of podiatry services, to spread information about foot care, and that any advertising should be for everyone.

I think advertising. I watch a lot of Māori Television. It's hitting all of us and that should be on every channel. With the things that are hurting our people in the health area, advertising is a good way of doing it. It should target the whole country. (Focus Group Participant)

I think the market should be flooded with podiatrist educators, community educators..... Whether these be educators, diabetes educator, we need to flood the market with it, because the message isn't getting back there. (Interview 015)

## APPLY CREATIVE THINKING

One participant talked about the need for creative health care provision in order to establish a more integrated process of preventive health provision.

The other potential is to look at broader aspects of what the podiatry service might do. It might offer sessions in preventative, if it's part of a community then being part of iwi health expo or there could be all sorts of creative ways in which they can raise their profile and their awareness and be part of a community and what happens, as opposed to just being a service 'over there'......One of things I see is that we are often focusing on the problems of diabetes as opposed to, "How do you have a healthy life living with your diabetes?" If you could have some kind of thing to help the people to understand that they can be healthy with diabetes and in some cases reverse it. That there is hope! .... That requires support and resourcing it's hard to know... (Interview 004)

Creative thinking was evident in the data in subtle ways. For instance, person recommended group support and interaction, people learning to do massage, for example.

What I'd like is interaction from us and we could make that tree grow. If there is somebody else that's having problems with their diabetes I want to be there because I've changed my eating habits. I'm doing a lot of reading in there and it's mainly eating Asian kai or Chinese kai with the herbs that they cook with (Focus Group Participant).

# SUMMARY OF ENABLERS TO GOOD MAORI FOOT CARE

Through a thematic analysis of qualitative data, this chapter has described the ways participants believed foot care works best for Māori. By breaking down the barriers described in Chapter One, Māori have recommended actions that are non-judgemental, implement Māori values and practices in health care, and create contexts that will be helpful rather than a barrier to foot care. They have recommended ways in which information and education processes would work more efficiently, and how the health care system, which presently creates its own major barrier to good foot care, could be redesigned in a way that is more efficient and effective for Māori requiring diabetes-related foot care, especially having a greater emphasis on health promotion and prevention. Through these ideas, concepts and suggestions, Māori indicated a way forward to empower them so their feet are fit for life.

# CHAPTER FIVE: QUANTITATIVE FINDINGS

## RECRUITMENT AND FOLLOW-UP

The final combined control and intervention group total number at the beginning of the study was 125 Māori. At the start of data collection, there were 60 in each of the intervention group and 65 in usual care group, however 5 did not receive the full foot assessment so were not followed up at 12 months. The final sample number at the end of the study was 97 Māori. There were 50 Māori in the intervention group and 47 Māori in the usual care or control group.

Twenty-two interviews were removed from the analysis sample through the life of the study. In the intervention group, 10 were lost to the project. In the control group a further 12 were lost to the project. Reasons for withdrawal included death (5), personal choice to withdraw - usually due to ill health, and leaving New Zealand.

The final dropout rates of 28% and 17% respectively are close to those estimated in the planning stages of this research. Table 1 demonstrates that there are no differences in the dropout rates across sex or age group. Examination of one of the key study measures ankle-brachial index (ABI) (Table 2) show no differences between participants lost to follow-up and those followed-up at 12 months. Therefore lost to follow-up is unlikely to be related to key status indicators. All further analysis will be focused on only the participants with complete data; 47 controls and 50 intervention participants.

		Control		Intervention			
	Base Line Data	Complete Follow-up Data	Drop- out Rate	Base Line Data	Complete Follow-up Data	Drop- out Rate	
Sex							
Female	47	33	31%	35	28	20%	
Male	18	14	26%	25	22	12%	
Age Group							
20-45	10	7	30%	15	12	20%	
46-55	13	9	31%	18	15	17%	
56-65	23	19	17%	16	14	12%	
66+	19	12	37%	11	9	18%	
Total	65	47	28%	60	50	17%	

TABLE 1 NUMBER OF PARTICIPANTS AT BASELINE AND ONE YEAR FOLLOW-UP

#### TABLE 2. COMPARISON OF KEY BASIC MEASURES FOR LOST TO FOLLOWUP

	Con	trol	Intervention			
	Followed	Lost to Follow-up	Followed	Lost to Follow-up		
ABI (summary)	1.03	1.00	1.12	1.10		
Median (IQR)	(0.94, 1.10)	(0.87, 1.14)	(1.01, 1.21)	(1.04, 1.23)		

IQR: Inter-quartile range (25%, 75%)

## PARTICIPANT CHARACTERISTICS

Only the participants with both baseline and follow-up data are examined in this and following sections.

The final overall control and intervention groups were quite dissimilar with regard to demographic characteristics as can be observed in Table 3. The intervention group as more likely to be male (44% versus 36% for controls), younger (median age 55 versus 59 for controls), more educated (56% having a qualification versus 43% for controls), and more likely to be in paid employment (50% versus 28% for controls). The two groups were similar with regards to social welfare benefits and personal income.

#### TABLE 3. DEMOGRAPHICS OF PARTICIPANTS

	Control		Inte	rvention	Total	
	n	(%)	n	(%)	n	(%)
Sex						
Male	14	(30%)	22	(44%)	36	(37%)
Female	33	(70%)	28	(56%)	61	(63%)
Age group						
20-45	7	(15%)	12	(24%)	19	(20%)
46-55	9	(19%)	15	(30%)	24	(25%)
56-65	19	(40%)	14	(28%)	33	(34%)
66+	12	(26%)	9	(18%)	21	(22%)
Qualification						
No Qualification	27	(57%)	22	(44%)	49	(51%)
Secondary Qualification	8	(17%)	2	(4%)	10	(10%)
Tertiary certificate /diploma	9	(19%)	23	(46%)	32	(33%)
University Degree	3	(6%)	3	(6%)	6	(6%)
Any social welfare benefits						
No	13	(28%)	17	(34%)	30	(31%)
Yes	34	(72%)	33	(66%)	67	(69%)

#### Table 4(ctd)

In paid employment						
No	34	(72%)	25	(50%)	59	(61%)
Yes	13	(28%)	25	(50%)	38	(39%)
Personal income						
\$0 - \$15000	8	(17%)	12	(24%)	20	(21%)
\$15001 - \$20000	8	(17%)	4	(8%)	12	(12%)
\$20001 - \$25000	15	(32%)	8	(16%)	23	(24%)
\$25001 - \$30000	7	(15%)	6	(12%)	13	(13%)
\$30001 - \$40000	4	(9%)	2	(4%)	6	(6%)
>\$40000	3	(6%)	10	(20%)	13	(13%)
Not Reported	2	(4%)	8	(16%)	10	(10%)
Total	47		50		97	

Utilisation of health services that are important to the management of diabetes are presented in Table 4. It is concerning that many participants had never visited a podiatrist (40%), dietitian (40%), optometrist (39%), diabetes educator (18%), or ophthalmologist (15%). All health services, except podiatry, show similar rates in both intervention and control groups; however 64% of the control group had never seen a podiatrist in comparison to 32% for the intervention group.

#### TABLE 4. UTILISATION OF HEALTH SERVICES

	Control		Intervention		Total	
	n	(%)	n	(%)	n	(%)
Number visits to primary health care services in last 4 weeks						
0	12	26%	17	34%	29	30%
1	15	32%	20	40%	35	36%
2	11	23%	7	14%	18	19%
3+	9	19%	6	12%	15	15%
Last visit to a ophthalmologist						
Within the last 12 months	20	44%	25	50%	45	47%
1-2 years	13	29%	14	28%	27	28%
2-3 years	3	7%	3	6%	6	6%
More than 3 years ago	1	2%	-	0%	1	1%
Never	8	18%	8	16%	16	17%

#### Table 4(ctd)

Last visit to a optometrist						
Within the last 12 months	16	34%	15	30%	31	32%
1-2 years	5	11%	4	8%	9	9%
2-3 years	0	-	6	12%	6	6%
More than 3 years ago	9	19%	4	8%	13	13%
Never	17	36%	21	42%	38	39%
Last visit to a podiatrist						
Within the last 12 months	9	19%	18	36%	31	32%
1-2 years	1	2%	10	20%	9	9%
2-3 years	3	6%	3	6%	6	6%
More than 3 years ago	4	9%	3	6%	13	13%
Never	30	64%	16	32%	38	39%
Last visit to a dietitian						
Within the last 12 months	16	35%	18	36%	34	35%
1-2 years	2	4%	4	8%	9	9%
2-3 years	5	11%	5	10%	6	6%
More than 3 years ago	4	9%	7	14%	13	14%
Never	19	41%	16	32%	38	40%
Last visit to a diabetes educator						
Within the last 12 months	33	72%	28	57%	61	64%
1-2 years	4	9%	7	14%	11	12%
2-3 years	0	0%	3	6%	3	3%
More than 3 years ago	0	0%	3	6%	3	3%
Never	9	20%	8	16%	17	18%

Table 5 presents data on how long since the participant was diagnosed with diabetes and a measure of their knowledge about diabetes management. The intervention group has on average been living with diabetes for a shorter period of time and correspondingly score lower on the diabetes knowledge scale.

	Co	ontrol	Inte	Intervention		Total	
	n	(%)	n	(%)	n	(%)	
No. years since diagnosis Median (IQR)	9	(3,18)	6	(3,8)			
0-4 years	18	39%	17	34%	35	36%	
5-9 years	5	11%	23	46%	28	29%	
10-14 years	7	15%	4	8%	11	11%	
15-19 years	7	15%	4	8%	11	11%	
20+ years	9	20%	2	4%	11	11%	
Diabetes knowledge scale Median (IQR)	5	(3,7)	3.5	(3.5)			
0-2	10	21%	12	24%	22	23%	
3-4	12	26%	20	40%	32	33%	
5-6	12	26%	13	26%	25	26%	
7-8	8	17%	5	10%	13	13%	
9-10	5	11%	-	-	5	5%	

TABLE 5. DIABETES HISTORY

Participants were asked whether they had been told by a health care provider whether they had any health conditions other than diabetes. Table 6 and

Table 7 present a summary of these questions. There are high rates of other co-existing conditions with rates from 25% to 90% among this population, which are likely to impact on their general health. In general there were no major differences between the control and intervention group, although the control group reports higher rates of all but athlete's foot within the lower limb status table (Table 7).

Told by a health care provider	Control		Inte	rvention	Total	
that you had:	n	(%)	n	(%)	n	(%)
Any eye problems	16	34%	19	38%	35	36%
Any heart/circulation problems	11	23%	13	26%	24	25%
High blood pressure	41	87%	41	82%	82	85%
Any heart operations or procedures	41	87%	46	92%	87	90%
Any bladder, kidney or urinary problems	13	28%	23	46%	36	37%
Any neurological conditions	40	85%	39	78%	79	81%
Any respiratory problems	24	51%	26	52%	50	52%
Any gastric problem	37	79%	39	78%	76	78%
Any musculoskeletal problems	19	40%	19	38%	38	39%
Any days lost from work or school due to illness/injury	19	40%	21	42%	40	41%

TABLE 6. HEALTH STATUS OF PARTICIPANTS

			ΔΝΤΟ
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Told by a health care provider	Co	Control Inter		rvention	Total	
that you had:	n	(%)	n	(%)	n	(%)
Peripheral vascular disease	15	32%	12	24%	27	28%
Intermittent claudication	17	36%	13	26%	30	31%
Peripheral neuropathy	12	26%	9	18%	21	22%
Foot ulcers	4	9%	3	6%	7	7%
Athlete's foot	9	19%	19	38%	28	29%
Any foot/leg problems	28	60%	33	66%	61	63%

Table 8 presents the comparison between the two groups for health behaviors such as tobacco smoking, alcohol consumption and physical activity. There are marked differences between the two groups with the intervention group having fewer current tobacco smokers (26% versus 43% for the control group), more participants undertaking enough physical activity to be sufficient to maintain health (28% versus 15% in the control group), and slightly more participants having had at least one drink of alcohol in the last year (62% versus 51% in the control group). Body Mass Index (BMI) was higher in the intervention group (median BMI=36.3, IQR 31.4-43.2) in comparison to the control group (median BMI=33.2, IQR 30.0-38.1) resulting in more intervention participants in the obese category.

	Co	ontrol	Inter	vention	Total		
	n	%	n	%	n	%	
Tobacco status							
Never smoked	11	23%	13	26%	24	25%	
Previous smoker	16	34%	24	48%	40	41%	
Current Smoker	20	43%	13	26%	33	34%	
Any alcohol in last year							
Yes	24	51%	31	62%	55	57%	
No	23	49%	19	38%	42	43%	
Sufficient physical activity for health							
Yes	7	15%	14	28%	21	22%	
No	40	85%	36	72%	76	78%	
Describe your physical activity over the last 6 months							
Not regularly physically active, no intention in next 6 months	4	11%	3	6%	7	8%	
Not regularly physically active, thinking about starting in 6 months	5	13%	8	17%	13	15%	
Some physical activity, not enough for regular activity	17	45%	17	36%	34	40%	
Regularly physically active, began 6 months ago	1	3%	7	15%	8	9%	
Regularly physically active, been so for longer than 6 months	11	29%	12	26%	23	27%	

TABLE 8. PARTICIPANT HEALTH BEHAVIOURS

#### Table 8 (ctd)

BMI						
Standard	5	11%	2	5%	7	8%
Overweight	15	33%	10	23%	25	28%
Obese	25	56%	32	73%	57	64%

The initial baseline podiatry assessment results are presented in Table 9 and

Table 10, demonstrating the presence of podiatric health issues for both control and intervention participants. However there are some differences across the two groups; with higher rates of intermittent claudication for controls (17% versus 2% for intervention group), lower rates of non-problems identified by the monofilament for intervention group (13% versus 56% for controls).

TABLE 9. BASELINE PODIATRY ASSESSMENT OF PARTICIPANTS

	C	ontrol	Inter	Intervention		otal
	n	(%)	n	(%)	n	(%)
Intermittent claudication (Edinburg classification)						
Yes	8	17%	1	2%	9	9%
No	39	83%	49	98%	88	91%
Neuropahy symptom score median (IQR)	0	(0, 6)	3	(0, 6)		
No symptoms (0-2)	27	59%	22	45%	49	52%
Mild symptoms (3-4)	4	9%	5	10%	9	9%
Moderate symptoms (5-6)	10	22%	11	22%	21	22%
Severe symptoms (7-9)	5	11%	11	22%	16	17%
Pulses						
Right Dorsalis Pedis	36	78%	31	65%	67	71%
Right Posterior Tibial	34	74%	23	48%	57	61%
Left Dorsalis Pedis	36	78%	27	56%	63	67%
Left Posterior Tibial		76%	24	50%	59	63%
Current ulceration	1	2%	2	4%	3	3%
Temperature gradient	26	59%	31	66%	57	63%

#### Table 9 (ctd)

	Control		Inte	rvention	Total	
	n	(%)	n	(%)	n	(%)
Neuropathy disability score Median (IQR)	2	(0, 4)	2	(0, 4)		
No symptoms (0-2)	32	70%	31	67%	63	68%
Mild symptoms (3-5)	7	15%	12	26%	19	21%
Moderate symptoms (6-8)	5	11%	3	7%	8	9%
Severe symptoms (9-10)	2	4%	0	-	2	2%
Monofliament (both feet)						
Median (IQR)	0	(0, 2)	1	(0, 2)		
0	24	56%	6	13%	30	34%
1	7	16%	6	13%	13	15%
2	3	7%	19	42%	22	25%
3-5	1	2%	7	16%	8	9%
6-10	6	14%	4	9%	10	11%
11-20	2	5%	3	7%	3	6%

#### TABLE 10. ANKLE-BRACHIAL INDEX

ABI	Control Intervention				
	Median	IQR	Median	IQR	
Right Dorsalis Pedis	1.00	(0.89, 1.08)	1.00	(0.92, 1.15)	
Right Posterior Tibial	1.00	(0.88, 1.07)	1.12	(0.95, 1.18)	
Left Dorsalis Pedis	1.00	(0.83, 1.07)	1.04	(0.93, 1.18)	
Left Posterior Tibial	0.95	(0.84, 1.07)	1.07	(1.00, 1.20)	
Summary*	1.03	(0.94, 1.10)	1.12	(1.01, 1.21)	

\* Average of maximum of DP and PT per foot

Table 11 shows the two groups are similar in some of the baseline musculoskeletal assessment measures, namely stiffness, fingers getting locked and numbness. However, muscular pain or swelling, stiffness or decreased motion in shoulders, and one of the key indicators; hands in positive prayer sign, demonstrate differences between the two groups.

Of specific concern is the hands positive prayer sign test appears to have **not** been collected in a consistent manner across all assessors due to the ambiguous wording of the survey. Cross checking with the intervention clinic information found only 10%-20% of intervention participants should have scored "Yes" that is, a failed the test. At 12 month follow-up the intervention group had about 20% failing the test which is more in-line with expectations, also according to knowledge about feasible physiological changes it is expected there should have been either maintenance or decrease in functionality.

	Control		Interv	vention	Total	
	n	%	n	%	n	%
Hands positive prayer sign?						
Yes	33	70%	44	90%	77	80%
No	14	30%	5	10%	19	20%
Total	47		49		96	
Stiffness in hands that affects ability to move them?						
Yes	25	53%	27	54%	52	54%
No	22	47%	23	46%	45	46%
Total	47		50		97	
Fingers get "locked" in certain positions?						
Yes	19	40%	19	39%	38	40%
No	28	60%	30	61%	58	60%
Total	47		49		96	
Numbness in fingers or hands?						
Yes	25	54%	25	50%	50	52%
No	21	46%	25	50%	46	48%
Total	46		50		96	
Stiffness or decreased motion in your shoulders						
Yes	17	37%	24	48%	41	43%
No	29	63%	26	52%	55	57%
Total	46		50		96	

TABLE 11. BASELINE MUSCULOSKELETAL ASSESSMENT

#### Table 11 (ctd)

Muscle pain or swelling						
Yes	17	37%	24	48%	41	43%
No	29	63%	26	52%	55	57%
Total	46		50		96	

## INTERVENTION CHARACTERISTICS

Transportation to the clinic was provided for intervention participants who were otherwise unable to get to the clinic. Only two participants required transportation to the clinic for their scheduled session (one for their initial assessment and another for their third intervention session).

The first step in the clinic intervention was a podiatry assessment, unless there were any other health issues needing to be addressed first. The initial clinic assessments were completed on the first clinic visit for 42 participants and on the second visit for 7 participants. Table 12 presents a summary of the intervention elements delivered to participants based on their needs. Based on the clinic assessment participants were then requested to return on an annual, six monthly or quarterly basis for follow-up treatment.

TABLE 12. BASELINE PODIATRY ASSESSMENT OF PARTICIPANTS

	Intervention Participants					
	n	(%)				
Initial Risk Classification						
Category 2	16	33%				
Category 3	23	47%				
Category 4	6	12%				
Category 5	2	4%				
Category 6	2	4%				
Number of Clinic Visits						
1	3	6%				
2	9	18%				
3	13	27%				
4	15	31%				
5	8	16%				
6	1	2%				
Received socks						
1 <sup>st</sup> visit	38	78%				
2 <sup>nd</sup> visit	8	16%				
No socks	11	22%				

Received cream		
1 <sup>st</sup> visit	43	88%
2 <sup>nd</sup> visit	21	43%
3 <sup>rd</sup> visit	10	20%
4 <sup>th</sup> visit	13	27%
5 <sup>th</sup> visit	2	4%
No cream	3	6%

Diabetic socks were provided for 38 participants (78%), with 9 receiving two pairs of socks and 11 receiving none. The lanolin cream was provided to 46 participants (94%), with 18 receiving one tube of cream, 16 receiving two tubes, 9 receiving three tubes and 3 receiving four tubes over the twelve month period.

Another important element of the intervention was the co-ordination of other services when the need was identified and encompassed a referrals system that was also followed-up in order to help facilitate the uptake of these services. Table 13 summarises the referrals and rates of uptake of these services. The highest uptakes were for the primary and secondary treatment services, with moderate uptake on the more preventative services such as smoking cessation, diet, and exercise.

TABLE 13 REFERRAL TO OTHER SERVICES

	Partic Refe	ipants erred	Service Uptake		
Referrals to	No.	(%)	No.	Uptake Rate	
Smoking cessation	6	12%	3	50%	
Dietitian	11	22%	6	55%	
Exercise group	23	47%	16	70%	
Diabetes Nurse, Educator or other Primary Care Nurse	34	69%	33	97%	
General Practitioner	12	24%	9	75%	
Orthopaedic surgeon	0	-	-		
Vascular surgeon	0	-	-		
External Diabetologist	0	-	-		
External Diabetes Centre	0	-	-		
External Secondary care podiatrist	3	6%	3	100%	
Orthotic services	10	20%	5	50%	

Table 12 (ctd)

# INTERVENTION IMPACT

The primary podiatry measures and diabetes knowledge were measured at baseline and at the 12 month follow-up. The following table (Table 14) presents the average unadjusted scores for the key indicators at baseline, 12 month follow-up and the average difference (means have been used as a purely indicative measure of centrality). Contrary to expectations there appears to be some improvements in monofilament and Neuropathy disability scores. The expectation was any underlying nerve damage, being measured by these scores, is unlikely to regenerate rather the intervention was expected to halt any further deterioration.

		Baseline	12 month follow-up	Change
Control	Neuropathy symptom score	2.41	3.11	0.63
	Neuropathy disability score	2.50	1.47	-1.09
	Monofilament	2.37	1.06	-1.21
	ABI (summary)	1.02	1.13	0.10
	Diabetes knowledge score	4.79	2.91	-1.87
Intervention	Neuropathy symptom score	3.35	3.88	0.68
	Neuropathy disability score	2.07	1.10	-0.93
	Monofilament	3.20	0.83	-2.35
	ABI (summary)	1.12	1.26	0.14
	Diabetes knowledge score	3.86	3.73	-0.12

TABLE 14 UNADJUSTED MEAN SCORES

The following tables (Table 15 and Table 16) examine whether there are any group effects (intervention versus control group), time effect (baseline versus 12 months) and group x time which identifies whether the intervention process had any differential impact in comparison to usual care. All models have been adjusted by age group, sex and number of years since diabetes was diagnosed.

The ankle brachial index showed significant differences at baseline and then significant increases in both groups, however there was no differential effect of intervention versus control. The diabetes knowledge score demonstrated significant differential results with the control group (although starting at a higher knowledge level than the intervention group) having a decrease in diabetes knowledge, whereas as the intervention group increased slightly.

		Baseline		Follow-up		p-values*		
		Adjust	ed mean (95% CI)*	Adjust	ed mean (95% CI)*	Group	Time	Group x Time
ABI (summary)	Control	1.02	(0.97, 1.07)	1.13	(1.06, 1.21)			
	Intervention	1.13	(1.06, 1.19)	1.22	(1.15, 1.30)	0.005	0.0003	0.80
Diabetes knowledge score	Control	4.95	(4.21, 5.69)	2.68	(2.10, 3.26)			
	Intervention	3.72	(3.18, 4.26)	3.77	(3.14, 4.39)	0.82	0.001	0.0005

TABLE 15 GEE REPEATED MEASEURES MODEL

\* adjusted by age group, sex, and number of years since diabetes diagnosis

Table 16 presents the results for the measures where there was a predominance of low scores and have therefore been categorised into no signs or symptoms (0-2) for the neuropathy symptom score and neuropathy disability score vs any signs or symptoms (3+), and those scoring 0 for monofilament vs those that had any problem sites (1+). Repeated measures logistic models have been undertaken on these categories.

The neuropathy symptom score showed no significant differences. The neuropathy disability score demonstrated significant decreases in scores from baseline to 12 month follow-up, however there were no group differentials i.e. both control and intervention participants improved.

The monofilament demonstrated significant improvements over time for both groups with a significant difference between the groups, that is the intervention group demonstrated significantly more improvement.

			Baselin	ie		Follo	w-up	Model		
		% At Risk*	Adjust R (95	ed Odds atio % CI)	% At Risk *	Adjusted Odds Ratio (95% CI)		Time	Group	Time x Group
Neuropathy symptom score	Control	41%	0.80	(0.42, 1.52)	55%	1.43	(0.70, 2.95)			
	Intervention	35%	1.45	(0.75, 2.83)	65%	2.55	(1.13, 5.76)	0.07	0.15	0.97
Neuropathy disability score	Control	30%	0.34	(0.14, 0.80)	21%	0.17	(0.05, 0.56)			
	Intervention	33%	0.83	(0.36, 1.91)	10%	0.09	(0.02, 0.36)	0.0009	0.83	0.07
Monofilament	Control	44%	0.92	(0.43, 1.97)	17%	0.21	(0.05, 0.30)			
	Intervention	87%	16.21	(5.50, 47.76)	21%	0.34	(0.14, 0.81)	<0.0001	0.0004	0.05

TABLE 16. REPEATED MEASURES LOGISTIC MODEL

\* adjusted by age group, sex, and number of years since diabetes diagnosis

% At Risk means a score of 3+ for Neuropathy symptom score or Neuropathy disability score, or a score of 1+ for monofilament

## DISCUSSION

There are marked differences between the control and intervention groups at baseline in both demographic and diabetes characteristics as well as the podiatry assessments. These differences have therefore had an impact on the potential power of the statistical analysis, as some of these key factors were needed to be included in the final models to adjust for these differences.

The participants' history of accessing diabetes and podiatry-related services plus the number of referrals to other services demonstrate Maori with diabetes are not accessing all the services they need.

#### **Podiatry Measures**

There are some concerns with the accuracy of some of the measures used in this study.

#### Musculoskeletal assessment

In hind sight it is easy to see that the musculoskeletal assessment question on hands positive prayer sign is ambiguous and given the number of assessors that have been involved in collecting the data some misinterpretation is not unexpected. It is evident that there was not consistent interpretation of this measure. If feasible, foot and ankle assessments that include range of motion at the ankle, subtalar, midtarsal and first metatarsophangeal joints should be incorporated in any future studies.

#### Monofilaments

Although there are significant effects demonstrated for the monofilament there is some doubt that the baseline intervention group measures are accurate.

The intervention group scored similar or better than the control group on most measures, is younger and more recently diagnosed than the control group, and is scoring similar to the control group at follow-up. And with a large number of the intervention group scoring 2 at baseline, which relates to one site on each foot lacking sensitivity; it demonstrates that a small error in measurement could be influencing the results.

The radius, length and elasticity of the nylon monofilament can affect the reliability of the instrument to consistently apply a 10g force to the skin. Furthermore, 28%, out of 50 monofilaments tested, deviated up to  $\pm 1.0g$  (Booth and Young, 2000). However, tests were conducted using load cells, thus variation in buckling forces may differ when considering the elasticity of the skin.

As this test was already widely used and advocated in many clinical guidelines, especially for diabetic patients, standardization of the method for the mono-filament test and studies to define the sensitivity of this method in clinical practice are important. Meanwhile, the sole use of a monofilament test to diagnose peripheral neuropathy is not recommended. The diagnosis of peripheral neuropathy can be made only after a careful clinical examination with more than 1 test, as recommended by the American Diabetes Association (American Diabetes Association, 2008. Tests for this clinical examination are vibration perception (using a 128-Hz tuning fork), pressure sensation (using a 10-g monofilament at least at the distal halluces), ankle reflexes, and pinprick (American Diabetes Association, 2008; Boulton et al 2005; Meijer et al, 2005).

#### Ankle-Brachial Index (ABI)

Although ABI is useful in the detection of people with moderate to no peripheral arterial disease, its inter-observer reliability is speculative in terms of detecting those with critical limb ischaemia (Matzke et al, 2003). Variability of ABI measurements by inexperienced clinicians can range between 0.10 to 0.15. However, intra-observer and inter-observer error for determining ABI were low indicating favourable reproducibility in a large scale study in which people with and without diabetes were included (Holland-Letz et al, 2007)<sup>1</sup>. There is less evidence on reliability and reproducibility of ABI measurement concerning people without symptoms or associated disease processes (Holland-Letz T et al, 2007). Variances in ABI readings can also be affected by calcification of the infrapopliteal arteries (Andros, 2004). Non-compressibility of these arteries can increase systolic readings and therefore elevate the ABI, although it is unclear by what increments these levels are elevated.

The error of measurement was identified as ranging from 0.10 to 0.15. Therefore changes of 0.10 and 0.14 identified in this study are within the bounds of measurement error, and indicate that ABIs are not particularly useful as measures in this type of study.

#### Final Models

Once the problematic measure monofilament measure has been eliminated there was only one factor showing significant change between the two groups over time, which was diabetes knowledge. The results demonstrate that the regular contact with a podiatrist, as part of a team of health care workers, enables Māori patients to retain the knowledge necessary for their wellbeing and maintenance of their diabetes, whereas those who do not have this regular contact are likely to slowly lose this knowledge.

The fact that there appear to be some issues in the measurement of the only podiatry measures, due to assessor variability, that have any significant results, demonstrates the need for better standardization of measurement.

# CHAPTER SIX: INTERVENTION PARTICIPANT FEEDBACK

Intervention group participants were asked at the end of the 12 month period their perceptions of the lanolin emollient creams, silver colloid merino wool socks, referral to other clinicians and education provided at the wānanga and in the clinic. This information has been incorporated with some information from the initial focus groups and observational information collected at the wānanga.

#### LANOLIN EMOLLIENT FOOT CREAM

Intervention participants were asked if they recalled being issued with lanolin emollient foot cream. Of the 50 participants interviewed at the 12 month follow-up; 41 responded "Yes", five responded "No", and four either did not know or did not answer the question.

The 41 who responded "Yes" were then asked how often did they use the cream in the last year. Twenty five (61%) said they used the cream daily, 7 (17%) said weekly, 6 (15%) said monthly and 3 (7%) said not at all or did not answer the question.

In one of the initial focus groups, participants talked about what they already knew before the study started.

We already know that it helps if you 'oil your feet and walk'. (Focus Group Participant)

Participants who had received the enhanced podiatry care intervention were asked in their second interview to comment on the experience of using the cream.

My boy (grandson) always massages my feet and he does that with the cream. I have never smelt any funny odours since he has been using the cream. (Q6 data)

The above quote is an indicator of the importance of using daily creams. By keeping feet free of infection, the cream reduced foot odour. By doing so, daily use of the cream changed both the wellbeing of feet, and improved a person's self perception.

Application (of the cream) keeps me aware as to the state of my feet. (Q6 data)

The cream helped when my feet became inflamed. It definitely had a good effect. I felt that it helped with the blood flow to my feet and I have noticed lately that my feet have not been all that hard and cracked. (Q6 data)

I thought the cream was great. It seemed different to other creams. Kept my feet nice and moist, especially between the toes. (Q6 data 145)

I found the cream to be excellent. It's not oily and doesn't affect my clothing. A great all round cream, not only for my feet. (Q6 data 183)

I have noticed the difference with my soles, heels and toes. (Q6 data 191)

It [the cream] also helps to relieve the pain in my legs, especially my calves. Q6 data 236

The cream has been awesome. My feet were rough and scaly. I have used it every day until I ran out. (Q6 data 241)

In addition to the above quotes, nearly all participants who were issued with the cream and used it regularly had positive comments to make. They noted the cream was 'really beneficial', 'very good', and they 'had no problem in recommending it to others'. They also reported it was difficult to find a cream as good as the one provided.

I have had no problems in recommending to others with diabetes. (Q6 data 106)

Participants talked about the benefit of the cream in preventing and treating cracks and hardness of the heel and dryness of the feet; giving feet a good texture; being soothing; for softening heels and cracks; making socks easier to wear; being used by other family members; not tainting other clothing; legs/feet feeling good after using the cream; feeling cool; being odourless; mess free; keeping feet moist; good for sandals; and non-greasy/oily with a pleasant odour.

Some noted a few difficulties with using the cream:

I think the cream is good but found it a bit sticky, especially when I went to bed. (Q6 data 240)

Data indicated the preventive benefits of the lanolin emollient foot cream used, indicating a need for policy change to provide the cream as a preventive health resource to people with diabetes.

Further, the suggestion that the cream prevents foot odours indicates the need for further research.

## SILVER COLLOIDAL MERINO WOOL SOCKS

Intervention participants were asked if they recalled being issued with special diabetic socks. Of the 50 participants interviewed at the 12 month follow-up; 37 responded "Yes", 9 responded "No" and 4 either did not know or did not answer the question. The 37 who responded "Yes" were then asked how often they used the socks in the last year. Twenty three (62%) said they used the cream daily, three (8%) said weekly, six (16%) said monthly and five (13%) said not at all.

Participants who received the enhanced podiatry care intervention were asked in their second interview to comment on the experience of using silver colloid merino wool socks provided. Three participants noted the socks were too hot for summer use:

Made my feet hot and sweaty. (Q6 data 150)

I found them unsuitable to wear with long boots. (Q6 data 220)

One person found the socks unsuitable for wearing with boots or long boots. Another, in comparison, found them good for steel capped work boots.

Really comfortable, good fit. The socks help when I have steel capped boots on at work. (Q6 data 213)

Despite some negative comments, many participants' responses were highly complementary about the merino wool socks, some not wanting to wait for washing and drying in order to wear them again!

Comments about the socks included stopping feet from drying; were wearable when feet swell; keeping heat in and helping the flow of blood; providing support for feet; were warm in winter; were cushioned and comfortable; stay up; don't mark the wearer's ankles like other brands; do not cause itching; are useable as slippers; were worn consistently; do not sweat even in the hot weather; are distinctly different to wearing normal socks; padding made them better to wear throughout the day; they were able to wear them on occasions where shoes were not worn - such as in a wharenui and around the home - and the markings for pressure points were described as helpful, although no additional details were provided about this aspect. Others commented they are hot in summer and may be difficult to wear with certain boots. Further, the socks were motivating and described as:

"Very comfortable, enough to motivate me to wear them everyday." Q6 data 214.)

I absolutely love the socks. They are luxurious, cushioned and lovely. I don't need shoes or slippers around the house. It's like walking on air. The markers for pressure points are also helpful. My moko keeps pinching them. (Q6 data 183)

Absolutely lovely. The marked pressure points were and are significant. Very easy on my feet. I have found that they are a bit too hot in the summer months though. (Q6 data 281)

The socks are absolutely fabulous and have become my everyday socks. I wear them 24/7 and that means wear, wash and dry and wear again. (Q6 data 166)

I would like to purchase more if I could. (Q6 data 273)

One participant was able to use the socks in a way that was educative for whanau members:

Everyone else wants my socks as well. I am constantly recommending to my whānau that they should have the socks and the cream as well. (Q6 data 223)

Despite the positive benefits of the socks, the following quote highlights the need for meaningful information and education that is understood by Māori/clients. One participant did not understand why they had received the socks and their preventive benefits, and therefore did not wear them. Others did not seem to realise their relevance to their condition.

Didn't really wear [the socks] much but the times I have worn them I found them really comfortable. I wear them on special occasions; otherwise I like to get around in bare feet most of the time. (Q6 data 169)

I can't really comment on the socks as I haven't worn them. The benefits you have explained about the socks has made a difference, I think I will wear them much more from now on! (Q6 data 172)

Participant comments indicated the special socks provided significant benefit in assisting the blood flow to their feet, keeping feet warm.

Is it possible the main benefit of the socks was decreased injuries because people are more likely to wear them? The findings in the qualitative data suggest further research is needed about the benefits of the socks, and whether they are helpful to the prevention of pathology leading to amputation.

A further component of the intervention was for podiatrists to refer participants to other clinicians when considered necessary.

Five participants described receiving a referral to another clinician. Referrals were made to another podiatrist for surgery, dietitians, diabetes [nurse] educators, and an ophthalmologist. Comments about referrals were mostly positive:

Yes, I have been referred to other health professionals. There has been a vast improvement in the condition of my feet over the last 12 months. (Q6 data 161)

Their involvement has made a great difference in terms of staying with a particular care plan. (Q6 data 236)

Participants found that the dietitian had helped them lose weight; provided helpful information about choosing the right food. The diabetes nurse helped them to stick to care plans, and overall, referrals to other professionals had assisted in improving foot care over the twelve months. However, referrals are not always helpful, as one participant said:

The Dietitian made recommendations for foods that I can't really afford. I just stick to the stuff I can afford. (Q6 data 227)

The quote above highlights the need for understanding a client's situation and making sure information provided is relevant to the constraints of daily life, such as making information contextually meaningful and affordable. Further, the above quote also highlights for some people nursing assistance and/or a nursing care plan can be helpful.

## PROVISION OF INFORMATION AT PODIATRY CLINICS

The podiatry intervention also included information provided by a podiatrist during clinic visits. Each person attended the podiatry clinic according to an individualised plan.

Three participants stated they did not receive information at the podiatry clinic at all, one person could not recall being given any information, and five did not think the education given at the podiatry clinic made any difference to their foot health. In contrast, 23 participants made positive comments about the information given at the podiatry clinic.

Positive comments about the provision of information during podiatry clinic visits included: the information was soothing; good follow up; good advice; and the benefit of being asked for feedback about podiatry care. Frequent comments were made about raising the participants' awareness in different ways. The particular benefits that participants described of one to one education was learning about the proper care of toenails, footwear and foot care. For instance:

The podiatrist told me that footwear is very important, especially when you buy new shoes. The podiatrist also showed me how to look after my toenails. (Q6 data 227)

It has been very helpful. For example, wearing the right footwear. (Q6 data 241)

One participant talked about learning preventive strategies:

Insight into the preventative side of controlling diabetes Q6 data 238

Relationships with clients, built over time, facilitated a form of knowing enabling a clinician to provide information that was meaningful at the client level of understanding.

Explains things well, [and] breaks down issues so that I can understand. (Q6 data 145)

In addition, clinicians were able to provide broader information, for instance:

Some good information also on how to control diabetes overall (Q6 data 169)

The data demonstrated the value of the podiatry time as an opportunity for education and sharing information as well as for professionals and clients to develop a connection.

## PROFILE EDUCATION WĀNANGA

The education wananga was attended by 11 participants. There were nine women and two men, with three facilitators.

## EDUCATION WĀNANGA WEEKEND EVALUATION

The education wānanga process was reviewed in order to generate useful information for future activities of this type. During the education wānanga, the Facilitator and organisers kept in mind the aims written for the wānanga were determined by stakeholders and participant data. It was provided on a marae, by Māori for Māori, and presented in a way that was Māori sensitive. Transport was also provided.

During the wānanga, participants were free to ask questions and opportunity was given for them to reflect on their own experiences and ideas. The meaning of diabetes, impact of change, new diets and ways of managing diabetes were discussed, blood testing, myth busting about diet, along with medication, foot care and eye care information were all provided. Exercises were conducted. Some of these, for example Tai Chi and other physical exercises, connected directly to the aim of the day (i.e. exercise improves diabetes management). Other processes, for example those designed to facilitate interaction, impacted diabetes in an indirect way as participants developed supportive connections with others who live with diabetes.

Participant interest was maintained through numerous teaching strategies and processes, such as the inclusion of warm up and 'getting to know you' sessions; respected guest speakers' giving opportunities for participants to ask and explore their own questions; and answers to those questions were explained. At the end of each session, the facilitator checked what people had learnt from the session, and whether people had changed in their level of understanding about that topic.

Comments and feedback from participants about the wananga were very positive, and participants were in agreement about how helpful it had been.

Of the 14 people who attended the education wānanga, six people said that they enjoyed it and found the information helpful or educational, while one person stated that the wānanga made no difference

to them. Another participant indicated while the wananga was good there was too much information in too short a time.

The wananga didn't make any difference really. (Q6 data 211)

The wānanga was a real eye opener. I didn't realise the sugar content of fruits, vegies and even bread. I attended both days. I intend to go to the next one. (Q6 data 241)

Yes, attended. It was very good, and I learnt many new things. ... ... I wanted the wānanga to go on. I enjoyed singing. Found it so interesting. (Q6 data 237.)

I attended the wananga but found that the volume of information, although good, was overwhelming. I felt that two days was a bit long. Perhaps the most benefit will come if the sessions are shorter and more frequent, targeting perhaps one issue at a time. (Q6 data 225)

I liked the doctors' involvement when they explained the different effects of the medications. This was the issue that stood out for me at the wānanga. (Q6 data 227)

Two participants talked about how important the interactive component of the wananga was:

People together learnt as a group. (Q6 data 237)

It was an ideal time for whanaungatanga where we could inspire and help each other. (Q6 data 273)

The data from the education wananga intervention is limited but indicates some direction for future knowledge transfer.

The comments demonstrated the importance to Māori of using a non-instructional approach, which would be appropriate in other settings. For some the wānanga contained too much information, and for others part of it was held at the wrong time of day and they were tired. Other feedback highlighted the importance of coming together as a group of people with the one condition where they could meet and share ideas.

On the second day of the wānanga, two new participants attended as other participants had encouraged them and explained the benefits of the programme. This may indicate that the size of the group may increase over time as people spread word through their community that any given programme 'is good'. This demonstrates that such processes need development time for 'word to spread' among the community that the people who run it are 'ok' and it is of benefit to community members. Thus the beginning of a programme will not look the same at the start and finish and reassessment of the attendance profile is always required.

The process of the education session demonstrated other issues as key processes that can be taken to account in future. For instance, having an experienced facilitator allowed not only the content to be provided by Māori but the process to be responsive to Māori needs and incorporated Māori knowledge. This was also a part of ensuring the process was both meaningful and fun for participants.

Nonetheless, despite positive feedback from participants indicating that the wananga was a success for them, there were a number of organisational issues such as change in personnel and external factors which made the education wananga complex or difficult in research terms.

#### SUMMARY

The majority of participants who received the lanolin cream and diabetic socks recalled receiving them. Of those that received the creams and socks; 61%-62% reported making use of them on a daily basis, demonstrating the acceptability of these item as part of a treatment programme.

The qualitative data obtained through this study indicated a number of issues of importance to further research, marketing of the socks and creams, and government health policy around the provision of preventive foot care resources for Māori. Qualitative findings also highlight the benefit to participants of the lanolin emollient creams and silver colloidal merino wool socks.

One major finding of the study closely aligns with Donald Beaven's recommendations made in the 1950s. Findings indicate the potential for benefit to Māori if podiatry preventive health resources, such as the lanolin emollient cream and culturally-wise education programmes were available free through a government scheme.

Māori who used the creams and socks stated, by using the creams problems occurred less often, therefore saving themselves trauma and the health care system money as less care and treatment was required in the longer term Preventive resources such as the creams kept people aware of their feet, prevented the cracks, fissures and hard dry feet that are precursors to significant foot pathology, decreased foot odor and the act of massaging it into the feet increased blood flow. Further, the lanolin emollient cream was not slippery, oily or sticky. It may also have benefits in reducing foot odor.

There is an urgent need to change the way we think about health care in terms of where the injection of funds occurs. This study raises the question: Why do we continue to fund health care that treats foot ulcers and results in frequent amputation when, if creams and socks were funded on prescription schemes free or at minimal cost for those who cannot afford it, problems would be prevented from occurring in the first place?

Observations from the wananga highlight the need for practical information on diabetes and maintenance of wellbeing for both community members with diabetes and their whanau. The majority of attendees found the information presented to be both useful and important to their well being and their whanau, but that there was too much information to digest in a single weekend wananga.

# CHAPTER SEVEN: DISCUSSION OF WHAT WORKS BEST TO REDUCE THE IMPACT OF DIABETES-RELATED FOOT DISEASE FOR MĀORI?

The findings demonstrate that when one takes the time and energy to develop a deeper understanding of Māori perspectives of health promotion, future activities can be planned in a way that results in better engagement with Māori clients. This research asked Māori their perspectives of diabetes related foot care for Māori. It is now important to listen to their voices and implement their suggestions.

Thematic analysis of the qualitative data obtained has been used to describe the barriers and enablers of good diabetic foot care for Māori, through focus groups, interviews and surveys.

The first section of this concluding chapter of the report reviews the study's aims and objectives. Five major barriers to foot care for people with diabetes were identified – stigma, unhelpful contexts, a lack of information and understanding and unhelpful structural processes. Four enabling factors were also identified: applying Māori values and practices to Māori foot care, creating helpful contexts, providing enabling and focused education programmes, and redesigning structural processes. Following this section, the implications of the findings are presented.

## DID THIS RESEARCH ACHIEVE ITS AIMS AND OBJECTIVES?

The purpose of the project was to improve lower limb outcomes for Māori who live with diabetes. The research achieved the aims of developing, implementing and evaluating a lower limb intervention for Māori with diabetes. Through focus groups, key informant interviews and stakeholder groups, every effort was made to ensure that the research, from conception through analysis to dissemination and publication was consistent with Māori aspirations and acceptable to Māori. It has created new knowledge that can be used to inform policy, funding decisions, and health service delivery and has provided a foundation for further research.

Through focus groups with Māori diagnosed with diabetes and key informant interviews, knowledge and perceptions of diabetes and diabetes-related foot issues, barriers and enabling factors relating to diabetic foot self-management, podiatry-related service content and delivery preferences, and indicators for evaluating success in foot care consistent with Māori community values, were identified.

The important factors necessary for a successful podiatry intervention for Māori were identified. An intervention was designed from the findings of the focus groups and in-depth interviews. The elements of the intervention design included: Ianolin emollient creams, silver merino colloidal socks, education wānanga and education at podiatry clinic visits, and referral to other professionals.

Questionnaires and foot assessments were undertaken at the start of the project and followed up 12 months later to evaluate the impact of the intervention in comparison to a control group. From

participant perspectives, the intervention was acceptable and effective for Māori and could be adopted widely by health services.

# SUMMARY OF QUANTITATIVE FINDINGS

The one factor that was significantly difference between the intervention and the control groups was diabetes knowledge. The intervention group retained their knowledge level between the initial assessment and the 12 month follow-up assessment, whereas the control group had a reduction in their knowledge level. This demonstrates that the podiatry clinic sessions in conjunction with referrals to other services enabled the intervention participants to retain the knowledge necessary to maintain their health.

Referrals were shown to be an important part of the intervention, with high rates of referrals to other important diabetes service providers. This highlights the importance of having a team of health care services working together to address all the needs of a diabetes patient.

The difficulties with the foot assessment measurements and the resultant differences between the intervention and control groups means that while there were no measurable differences in foot status, it is possible that changes may be more detectable with either a longer follow-up time or with better standarisation of foot assessment measurements.

A secondary finding was that the majority (64%) of the participants from the control group had never been seen by a podiatrist, many of these participants had very poor foot status. This raises concerns that Māori patients of clinics without onsite podiatry services may not be receiving the education and treatment necessary to take care of their feet, thus ensuring that minor foot injuries do not progress to major complications such as amputation.

## SUMMARY OF QUALITATIVE FINDINGS

Thematic analysis of qualitative data obtained in this study has been used to describe the barriers and enablers to good podiatry care for Māori.

## BARRIERS TO GOOD MÃORI FOOT CARE

The barriers identified by participants were summarized into four categories:

- Stigma
- Unhelpful contexts
- Lack of information and understanding
- Unhelpful structural processes

STIGMA

Findings suggest various forms of both external and internal stigma continue to impact on Māori foot health care, each form of stigma reinforcing the other. Despite recent advances in equitable treatment, Māori continue to feel some health professionals treat them with disrespect.

Stigma is particularly evident when health care professionals, regardless of whether or not there is any intent to be reassuring, dismiss Māori questions. Requests for explanations and information are often trivialised and treated as irrelevant by health care workers.

Meaningless answers are provided to questions resulting in an ongoing lack of understanding, as well as a sense of alienation and disconnection from one's own condition. Further, people do not like to ask again when their questions have been dismissed before.

Various forms of stigma compound each other. Stigma is also absorbed and internalised by Māori and reinforced by structural processes. Māori describe a sense of shame associated with having foot problems as they absorb and reflect stereotypes such as those about being overweight, being Māori, and being older. Whakama and guilt was a major obstacle to early help seeking, resulting in small problems becoming major ones.

#### UNHELPFUL CONTEXTS

A number of barriers to foot care occur in unhelpful contexts which were described as being related to: belief, personal, whānau, community, work and clinical contexts.

Unhelpful contexts include any traditional belief systems Māori may have that create challenges for people with diabetes. For example, not wearing shoes inside often in situations where foot injury can occur; or in the more general diabetes context, the kai provided at hui and celebrations. There is a need for Māori to explore such belief contexts in discussion with health care specialists, e.g. podiatrists, and to seek solutions in their own way, with, and for their own people.

*Personal contexts* also included unhelpful thinking processes, such as the difference between knowing what to do and acting on that knowledge. Additionally, diabetes is a diagnosis impacting on one's self-esteem and self-perception and can be hard to accept. Further it is likely to raise fear of the diagnosis and of involvement with the health care system.

*Whānau and community contexts* also create barriers when a lack of whānau support is perceived. Whānau joke about diabetes or Māori with diabetes who prioritize whānau and community needs over their own need for self-care. There is an urgent need for research to demonstrate how 'caring' can be done, while maintaining caring for self.

An important and powerful barrier to the majority of Māori diabetes care continues to be when whānau are not involved and engaged. For example, when clients and whānau do not understand the full impact of diabetes and are held back by unhelpful historical whānau patterns. Very little previous focused attention has been given to whānau and how whānau can successfully engage in diabetes care. Further, there is minimal information about how whānau can be assisted to be involved.

Participants called for greater whānau/family engagement according to Māori beliefs and traditions. Māori participants in this research believe the implementation of such a policy is necessary to improving foot care, and possibly health care, among Māori.

*Whānau histories* can create learnt fears, and a sense of resignation to a genetic imperative. However, little attention has been paid to whānau or community engagement and what that actually means in a Māori context, how it can be best achieved for the most positive outcomes for people living with diabetes.

*Work and clinical contexts* also create barriers. People with diabetes are part of a broader community where further barriers can occur for good foot care. Work contexts impact health, yet little research demonstrates how good foot care for working Māori living with diabetes can be supported in work environments.

#### LACK OF INFORMATION AND UNDERSTANDING

Lack of information and understanding barriers were facilitated by inappropriate information being given to Māori, which included both culturally and age inappropriate information. Information often lacked a credible source for Māori clients. Health care workers often provide a limited 'menu' of options for clients as they are not always aware of the extensive range of services available.

Participants explained that in clinical contexts a lack of connection with clinicians also created alienation and a sense of an uncaring and disrespectful health care system. Further, when Māori seek assistance from a health care worker in an urban context such as in this study, not being 'known' to the professional can subsequently stimulate a lack of consistency in information, and Māori can become 'lost' within a confusing health care system in which professionals are too busy to get to know them.

## UNHELPFUL STRUCTURAL PROCESSES

The present health care system creates barriers to good Māori foot care through unhelpful structural processes. These processes were analysed into six themes: the philosophy of health care; lack of Māori providers; lack of funding sustainability; cost of good foot care services; immobility and lack of service coordination.

The *current philosophy of health care*, and thus of foot care is medical, treatment oriented and individualized, and places emphasis on treatment not prevention. It does not support funding for preventive resources or ensure sustained funding for good foot care services. An adequate recruitment and training process has not, to date, ensured a strong Māori workforce, nor does it ensure culturally responsive providers.

*Costs* of foot care were unaffordable to many Māori in this study and include cost of good preventive resources such as the lanolin emollient cream, silver colloidal merino wool socks and specialized podiatry care.

Focused and meaningful education about foot care is not readily available to Māori, nor to the healthcare providers.

In addition, *transport and access* are often either expensive or problematic because of the immobility associated with advancing age or disease. According to the literature review (see Appendix One), the practicalities and cost of transport are often thought about, but many issues such as immobility remain unresolved for Māori.

Additionally, there are situations in which Māori do not use services provided free. There is a limited understanding of why this may occur and further research is needed to understand this issue.

Services are poorly coordinated. Health care professionals and clients are either uninformed, or informed by accident and good luck, about the range of foot care options available rather than through education and information. Clients are either told about a limited menu of services or sent to a confusing array of services in different places, frequently hearing mixed messages which, in some cases, can be dangerous in the confusion they create.

#### IN SUMMARY

Foot care is a crucial part of the rich tapestry that comprises the complex daily life for Māori who live with diabetes. Participants' stories highlight the urgent need for action that prevents foot pathology from occurring in the first place, rather than treating it when it becomes too late. Participants described multiple barriers to foot care, but also put forward many ideas, processes and strategies to facilitate good foot care at personal, whānau, community and health care system levels. They talked about what good foot care would look like to Māori. They also discussed what would be needed to turn the above barriers into enablers.

## ENABLERS TO GOOD MAORI FOOT CARE

Analyses demonstrated four key components to "What works best for Māori to reduce the impact of diabetic foot disease?" These key components were:

- Implement health care practices that are relevant and responsive to Māori
- Create helpful contexts
- Implement enabling, focused education and information programmes
- Redesign structural processes.

## IMPLEMENT HEALTH CARE PRACTICES THAT ARE RELEVANT AND RESPONSIVE TO MAORI

Analysis of participants' qualitative responses indicated that if genuine prevention of foot pathology is to take place, it is no longer appropriate to cling to a Western model of health care based on individualistic and medical models. By listening to the voice of participants, this identification of enablers to Māori foot care has shown it is important that *Māori knowledge, values, meanings, ways of life and practices inform the provision of foot care*. Applying Māori values and practices enables both clients and providers to provide/receive a service that is acceptable by, and empowering to, Māori.

It is important to establish the interpersonal connection necessary to underwrite the provision of services which can then be developed to enable the provision of information and skills that are useful and practical, and establish helpful contexts for support and learning.

Culturally responsive providers are needed to ensure genuine and helpful connections with Māori clients, and provide important crucial and locally appropriate information. Greater connections with Māori clients would also ensure a more holistic and integrated approach to clients as people with complex personal, whānau, and community lives.

Data showed how stigma continues to occur in health care contexts, highlighting the need for cultural responsiveness to be an intrinsic part of health care workers practice. Training is provided in all undergraduate and postgraduate health courses as well as being readily available in the health workplace, therefore there must be issues of putting the practice into operational procedures.

As the literature discussed (Appendix one), many Māori in the study would prefer services for Māori to be created and delivered by Māori. The sustained and continuous training of Māori as podiatry and health professionals is recommended. However, in the interim, there is a lack of Māori health providers. Participants agreed it is crucial that health care providers be culturally responsive in order to better create relationships in the appropriate way for Māori and to provide information in a way that can be understood and used.

#### CREATE HELPFUL CONTEXTS

Helpful contexts are essential to ensuring that what works best for Māori is implemented at an individual, whānau, community, work, and clinical context.
Helpful contexts involve individuals in self engagement with diabetes to regain a connection between mind, spirit and body. A personal plan developed by the individual and their whānau, in conjunction with a health professional, could facilitate this process, yet very little attention has been given to what such plans are and how they would most benefit Māori. Further research is needed to explore the development of personal plans for health.

The involvement of whānau/community, connection with others, and mind/body connection may be major keys to solving significant foot pathology for people with diabetes.

Helpful whānau, community, work and clinical contexts could also provide realistic and meaningful assistance and support. Engaging whānau and community in diabetes care can have the simultaneous benefit of increasing awareness of their own risk. It is necessary to explore who, with whom, and under what circumstances can whānau/community engagement in foot care best be developed and sustainably funded.

In He Korowai Oranga Māori Health Strategy (Ministry of Health 2002b) the New Zealand Government have identified the need for greater whānau support and the written policy needed for this to occur. Māori in this research suggested the implementation of such a policy for improving foot care, and possibly health care, among Māori is important and necessary.

It is important therefore to explore how the boundaries of current health care could be extended to ensure complete and effective engagement of whānau and community in assisting and supporting people with diabetes. Currently, although it is acceptable practice for whānau to attend doctors visits, very little funding is available to educate whānau about how they can support or assist whānau members with diabetes, nor is it clear what forms such assistance and support could take. Further research and exploration would enable us to create more helpful whānau/community contexts in which the best possible Māori foot care can be delivered is necessary.

It is also clear that other helpful contexts can be created in work and clinical contexts. More information about work situations is required before recommendations can be made as to how they could best provide support to Māori employees with diabetes. Clinical contexts however, require greater connections with Māori in order to establish more effective clinical care.

# IMPLEMENT ENABLING, FOCUSED EDUCATION AND INFORMATION PROGRAMMES

Enabling and focused education programmes and the provision of crucial information could be provided through multiple sources and at appropriate venues and times, while at the same time ensuring the content is relevant, useful and practical by a Māori client base. However, qualitative data demonstrates that the provision of information is not enough. Māori need information shared within a relationship with a health professional that cares about them, and develops that relationship in the right way for Māori. Such a health professional would provide meaningful information to Māori clients as individuals and as a whānau within a given context. Information should contain Māori examples and references that are cultural, locality, age and gender appropriate, and adequately answers their questions in a way that does not trivialise them.

# REDESIGN HEALTH SYSTEMS

The analysis shows the need for a health care system redesign that shifts the way funding, services and education are provided, in order to ensure the best foot care is provided to Māori in a format that is most acceptable to Māori.

First, it would be necessary to change from treatment oriented health care, to one that funds prevention strategies. The findings of this study raise the question: Why do we continue to fund health care that treats pathology rather than preventing it in the first place? By funding preventive health resources (such as lanolin emollient cream) before problems occur, foot pathology may be stopped, or at least halted for some time. Indeed, when the right preventive resources are available and consistently used, problems are less likely to begin in the first place.

Developing a 'whole package' would enable more integrated and coordinated foot care for Māori that was quality assured. Integrating culture into the clinical context requires ongoing training of culturally responsive and competent providers, as well as the provision of sustainable funding for podiatry programmes, training and client education. Sustainable funding would provide affordable and accessible support and foot care for individuals with diabetes.

This study reinforces the need for a greater Māori podiatry workforce (Ratima, Brown et al. 2007). Participants also noted the community could be made more aware through the advertising of podiatry services, where they are, and what they offer. They further noted information about these services should be shared with other health professionals, so Māori receive information and are referred to podiatry services in a timely manner.

# IN SUMMARY

There is strong potential for the provision of easily accessible podiatry services as a part of a team approach through primary health care services to bring about positive outcomes and equitable care for Māori living with diabetes. There is also a need to ensure that Māori whānau and communities have the authority and control with which they can self-empower and take a leading role in the planning of foot care from their perspective in order to implement the findings of this report.

# LIMITATIONS OF THIS RESEARCH

The findings of this report were obtained by interviewing Māori within the urban environment of Auckland. Thus, they do not necessarily apply to all Māori, particularly rural Māori or to people of other cultural traditions and cultural contexts. All Māori communities are different and unique in some way. Therefore before being applied within any community the findings of this study should be examined, discussed and adjusted according to the needs of the local people.

The resultant interview survey used in this intervention was long (70 questions plus a foot assessment), and it was reported that some participants had difficulties in completing the full survey. However due to the complexities of the relationships between lifestyle, diabetes and lower limb status, it was not possible to reduce the amount of data necessary for a valid and robust statistical analysis.

There are many hurdles in undertaking a research project, and one of the major hurdles encountered in this research was multiple changes and shifts in the core investigation team and field assessment staff. Most critical was having multiple (sequential) people being responsible for the project management and community engagement role/s over the course of the project. The result of this was that at various stages in the project there was a lack of engagement with the community and stakeholders, which also resulted in a hugely extending the duration of the research project. Most importantly there were key members of the team after each changeover of staff who managed to bring the project back on track and through to completion. However in the process there was some impact on the quality of some of quantitative data collected as reported in Chapter Five, and on the intervention group participant engagement in the education wānanga as reported in Chapter Six.

# RECOMMENDATIONS OF THIS RESEARCH

The following recommendations have been made for greater effectiveness, appropriateness and relevance of foot care services for Māori, with the aim to reduce lower limb amputations among Māori.

# APPLY MĀORI VALUES, BELIEFS AND PRACTICES IN MĀORI FOOT CARE

There have been some consistent themes across all components of this research that should be addressed in the delivery of all healthcare services and especially foot care services:

- Establishing and maintaining meaningful relationships with Māori
- Recognizing and respecting Māori cultural values, beliefs and practices
- Incorporating these values, beliefs and practices into working with Māori by using Māori models and frameworks
- Reinforcing the need for ongoing education and training in working with Māori in a culturally responsive and competent manner
- Critical analysis of the historical and contemporary socio-economic and political influences on Māori

# CREATE HELPFUL CONTEXTS

# CULTURE

Explore healthcare and education options that combine tradition with prevention and intervention
 Conduct an exploration of how belief systems related to Māori culture may impact on foot

care e.g. situations where protective footwear is not worn, shortage of Māori podiatrists

# WHĀNAU AND COMMUNITY ENGAGEMENT

Engage whānau in healthcare visits, education and development of health plans

- Establish connection between foot care providers and educators with the whānau in the Māori way
- Funded and properly supported whānau engagement in foot care, which includes foot care professionals and educators making time for whānau to receive information and ask questions
- Facilitate whānau engagement with foot care at all levels through dialogue, the power of knowledge, shared resources and skills
- Whānau, alternative therapists, and allied health providers be invited to take a greater role in foot care e.g. toenail care, massage, traditional healing strategies
- o Explore ways in which to educate whanau about foot care

Develop community based (ie Māori) health and education programmes based on community identified needs

- o Explore ways in which to educate and empower community in foot care
- o Mobilize community resources to meet community needs for foot care
- Share information between community and providers
- Celebrate connection
- Explore avenues for engagement for future generations, e.g. school programmes

# ENSURE MINDFUL SELF ENGAGEMENT

Recognition of the impact of the societal, cultural, community and whānau influences on an individual's engagement in the diagnosis and self management of diabetes:

- o Identify and address internalised stigmas for Māori related to diabetes and feet
- o Assistance to accept the diagnosis of diabetes with mindful self engagement
- Knowledge and information to increase acceptance of the consequences of a diagnosis of diabetes
- Develop an understanding of the impact of diabetes on one's feet and how to better prevent foot pathology through awareness of those things that cause injury, signs and symptoms to watch out for, warning signals of something going wrong, and how to act when things happen or go wrong with feet

# HEALTHCARE SERVICES

# REDESIGN STRUCTURAL PROCESSES

Ensure that funding bodies and providers actively adopt a preventive philosophy of foot care – preventing problems before they occur will reduce the incidence of minor feet problems resulting in amputations

- Create a health care culture that visibly supports preventive health care
- o Ensure sustainably funded preventive health resources

- Explore how to best fund effective foot pathology prevention such as the provision of socks, high quality creams and education wananga
- Fund prevention equally with treatment

# INCREASE CLINICAL CONNECTION WITH MAORI WHO NEED FOOT CARE

Explore how health care practitioners and services can establish more meaningful connections with Māori clients e.g. if doctors rotate regularly, perhaps continuity of nurses and front desk staff can be ensured

- Develop supportive, informed, connected teams of practitioners with consistent patient relationships
- Develop culturally responsive teams of practitioners with foot care skills
- o Explore current system for communication and identify cultural knowledge gaps
- Ensure regular health education contact between health providers and Māori living with diabetes in order to retain knowledge about how to manage life with diabetes

# ESTABLISH COORDINATED AND INTEGRATED SERVICES

Establish multidisciplinary teams of culturally responsive practitioners that are able to integrate the services and education they provide

- Agreements that facilitate care coordination within and across organizations and community
- Increase practitioner and community awareness of the services that are available, where they are, when they are available, who they are provided by and how much they cost patients
- Advertise all services, education and programmes widely, e.g. through the media
- Create "one stop" diabetes care shops
- Whānau, alternative therapists and allied health providers to take a greater role in foot care e.g. toenail care, massage, traditional healing strategies

# EVALUATION OF SERVICES AND EDUCATION PROGRAMMES

Ensure there are evaluation processes for all service and education programmes that test whether Māori responsiveness and relevance is achieved

- Create evaluation programmes to ensure Māori are able to be heard in feedback mechanisms
- Ensure that all programmes are revised according to Māori feedback and evaluation on a regular basis
- Ensure all Wānanga and education processes have adequate and appropriate linked evaluation strategies and are quality assured

# MEDIA

Ensure a range of relevant information about preventive foot care that is culturally responsive is available in various forms through relevant media

 Ensure 'follow-up' information in appropriate forms e.g. brochures, pamphlets, recall visits and reiteration of information given • Disseminate information appropriately and adequately to ensure health care providers are all aware of all options for patients

#### FUNDING

Ensure healthcare and education is relevant, accessible, available and affordable to every Māori living with diabetes

- Sustainable funding to podiatry services
- Explore more accessible and affordable alternative options that are currently available for instance, outreach services in homes, mobile buses in communities, foot care linked to other activities e.g. education events
- Explore options to ensure that funded services are appropriate, funded, and relevant to patients to increase use and attendance
- Review Māori non attendance at free services and identify ways in which attendance rates can increased e.g. are services inappropriate, lack credibility, too busy, not making connections with Māori, inaccessible, threatening in some way and so on? Do personal, whānau or other contexts create barriers to attendance?
- Fund foot care programmes in an ongoing basis with regular feedback, revision and review established to ensure quality

# PROVIDE ENABLING EDUCATION PROGRAMMES AND HEALTHCARE WORKFORCE

# HEALTH PROFESSIONAL EDUCATION AND RECRUITMENT

Education of health professionals to ensure recommendations given by foot health providers to patients is appropriate in terms of

- Cultural responsiveness
- Developing genuine connection with Māori patients in the way that is right for Māori before providing information
- Appropriate age and gender focus
- Person appropriate
- Based on Māori understandings and Māori world views
- o Locally or contextually appropriate for client
- Ensure Māori cultural responsiveness is always undertaken in the healthcare workplace and integrate culture into the clinical context
- Recruit and train more Māori in foot care
  - Undergraduate training set up to increase Māori workforce
    - Ensure undergraduate curriculums are not stigmatising or inappropriate to Māori students
    - Create effective alternatives in the absence of Māori workforce
    - Establish more Scholarships for Māori foot care students
    - Career advice and assistance for young Māori from established foot care programmes

Work in with Māori for instance, contractors to work in with Māori in order to ensure provision of services e.g. podiatry, where they are currently unavailable

# ENABLE MEANINGFUL PATIENT EDUCATION AND WĀNANGA

Plan training programmes and wānanga to meet the needs of local Māori clients and their whānau
 Encourage participation of whānau

- Ask Māori clientele where and when best to conduct Wānanga, education programmes and services
- Ensure venues are accessible and provide transportation and childcare options where required
- Advertise training programmes and wananga in adequate time to ensure good attendance
- Ensure that the food provided at wānanga is appropriate for a diabetic and consider meal breaks as workshops
- Consider times that are tiring, low blood sugar levels etc do not have education during these times
- Consider options for multi staged events for workers and non workers to attend

Ensure content and structure of education programmes and wananga are adapted to meet the needs of local Maori clients and their whanau:

- Ensure that the content is what people want to know, rather than what foot care professionals wants to teach about
- Crucial information is provided in an understandable, useable, meaningful format
- Ensure information is delivered by a source that is credible to Māori clients and their whānau
- Provide information that will make a difference on an individual and whānau scale i.e. 'what matters to this person?' 'what matters to this person's whānau?'
- Ensure that foot care providers understand not to ignore questions with reassuring statements such as 'You'll be fine". This is perceived as dismissive and uninformative
- Create questioning environment where all questions are encouraged, and person related culturally appropriate answers are given
- Use traditional skills and 'ways of knowing' in combination with modern knowledge when presenting information
- Explore ways in which to adapt generic programmes with local people
- o Consider ways to address local concerns about foot care
- Use traditional skills and 'ways of knowing' in presenting information
- Key foot care topics should include: taking care of feet, preventing injury, footwear options, examining your own or someone else's feet, ensuring good blood circulation to feet e.g. appropriate and achievable exercises, and the relationship of nutrition and exercise to healthy feet
- Ensure evaluation and feedback processes are undertaken to improve future sessions

# RESEARCH

- Conduct research that will identify ways to empower whānau and community with the knowledge and skills to understand how to help whānau and community members with diabetes and foot care related needs
  - Explore how whānau and community full participation in foot care can best be funded e.g. education and health promotion
  - Explore the perspective of Māori with diabetes about involving whānau
  - Explore whether and how whanau would like to be involved in foot care
  - Māori to further explore what Māori cultural values and practices are relation to foot care
  - Research and explore traditional foot care strategies and emphasize those that continue to be helpful in modern contexts
  - Conduct research about the connection of spiritual health to the wellbeing of feet
- Conduct research that compares the benefits of the creams and socks used in this programme with alternative types of socks and creams to establish the most effective in preventing foot pathology
  - Conduct clinical trials about forms of diabetic foot injury prevention socks designed to prevent foot complications to diabetic feet when shoes are not worn
  - Research and evaluate polices on how preventive foot care resources (such as socks, creams, education) are funded
- Conduct research that will identify how to establish workplaces supportive to the prevention of diabetic foot complications
  - Research work environments to explore ways in which workplaces create barriers to good foot care e.g. require people to stand all day
  - Explore how to empower workplaces to support and facilitate good foot care for Māori (and others) with diabetes

# CONCLUSION

The findings demonstrate that when one takes the time and energy to develop a deeper understanding of the Māori perspective of health promotion efforts, future activities can be planned in a more grounded way with more meaning for participants. It is no longer adequate to accept the status quo in Māori foot care. Participants' stories highlight the urgent need for action that prevents foot pathology from occurring in the first place, rather than treating it once it is too late. If we truly wish to make a change in foot care for Māori, new perspectives of health care is the first step to ensuring that, despite a diagnosis of diabetes, Māori living with diabetes are empowered to ensure that their feet remain healthy feet for life.

# GLOSSARIES

# GLOSSARY OF MĀORI TERMS

Awhi – support Hapu – sub-tribe lwi – tribe Hinengaro – mental dimension Hoha bored, wearied Kai - Food, meal Karakia – praver Kaumatua – Māori elder Kawakawa pepper tree used for ceremonies Korero - speak Mana - prestige Manaakitanga - to care for others Mate Māori – Māori sickness Mirimiri rub, massage Moko a term of address used by an older person for a grandchild or a young child. Short for 'mokopuna' Mokopuna grandchild **Powhiri** – to welcome Rangatira - leader Ropū group Rongoā treat, apply medicine **Tika** - Tika literally means "correct", doing things the right way Te reo Māori (Māori language) the ancestral language of the tangata whenua Tangata whenua – people of the land **Tinana** – the physical dimension Tapu – sacred Te Whare Tapa Wha –a model of Māori health Tikanga Māori – Māori custom **Tūroro** noun: sick person, invalid, patient Wānanga - Seminar, conference or forum Waewae Leg, foot, footprint Wairua – spirituality Whānaungatanga - relationships Whakapapa – genealogy Whānau – the family dimension Whānau ora – family wellbeing Whakataukī - Proverb

The Māori Dictionary website Te Aka Māori-English http://www.Māori dictionary.co.nz.

# **GLOSSARY OF TERMS**

**Charcot's Foot** Charcot foot is a progressive degenerative condition that affects the joints in the feet. Charcot foot affects the metatarsal, tarsometatarsal, and tarsal joints, which are located in the forefoot and mid-foot. Charcot's foot is associated with nerve damage (neuropathy) that decreases the ability to sense stimuli, including pain, and decreases muscular reflexes that control movement. As a result, the joints in the feet are subjected to repeated trauma and injury, causing progressive damage to the ligaments, cartilage, and bones. Charcot foot occurs most often in people with diabetes mellitus. It occurs at the same rate in men and women and develops in both feet in approximately 20% of cases. According to the American Diabetes Association, 60–70% of people with diabetes develop peripheral nerve damage that can lead to Charcot foot and about 0.5% of these patients develop the condition. In most cases, onset occurs after the age of 50, and after the patient has had diabetes for 15 to 20 years (Podiatry Channel 2009).

**Diabetes Type 2** Type 2 diabetes is a chronic (lifelong) disease marked by high levels of sugar in the blood. It begins when the body does not respond correctly to insulin, a hormone released by the pancreas. Type 2 diabetes is the most common form of diabetes. (Medline Plus 2009)

**District Health Board (DHB)** Health management units accountable to the Minister of Health. DHBs have existed since 1 January 2001, when the New Zealand Public Health and Disability Act 2000 (Ministry of Health 2000d) came into force.

**HbA1c** Glycated haemoglobin (*hemoglobin A1c, Hb<sub>1c</sub>, Hb<sub>A1c</sub>, or A1C*; sometimes also *HgA1c*) is a form of <u>haemoglobin</u> used primarily to identify the average <u>plasma</u> <u>glucose</u> <u>concentration</u> over prolonged periods of time (Larson, Horder et al. 1990).

**Primary Health Care** The first level of contact that individual, families, and the community have with the health system. The care given is therefore general (that is, not specialist), comprehensive (covers physical and mental well-being, and includes both preventative care as well as medical treatment), continuing (in that an individual often visits and establishes an ongoing relationship with a particular general practice), and accessible.

**Primary Health Organisations** Not-for-profit provider organisations are funded by DHBs to provide primary health care services for an enrolled population. They bring together general practitioners, nurses and other health professionals (such as Māori health workers, health promotion workers, dietitians, pharmacists, physiotherapists, psychologists and midwives) in the community to serve the needs of their enrolled populations. A primary health organisation provides services directly by employing staff or through its provider members.

# LIST OF ABBREVIATIONS

DHB District Health Board

GP General Practitioner

PHO Primary Health Organisation

# APPENDICES

# APPENDIX ONE: LITERATURE REVIEW: WAEWAE TAPU: THE SACRED FOOT (BROWN AND TAUPUA WAIORA 2007)

Main writers and contributors: Rachel Brown, Nick Garrett and staff of Taupua Waiora including among others Liane Penney and Mihi Ratima.

A *Chronic Health Condition*<sup>3</sup> has been defined as "a condition which has lasted, or is expected to last, six months or more" (Australian Bureau of Statistics 2007). Diabetes is a significant chronic condition, and a health problem that affects people of all ages and all populations (Baxter 2002; Waitemata District Health Board 2002). Estimates in 2004 suggested that diabetes affected approximately 246 million people worldwide, and that by 2005 this figure would increase to 380 million (Viswanathan, Madhavan et al. 2005; International Diabetes Federation 2007).

The social and economic situation in which a person lives significantly impacts their health and well being, and the rate of chronic conditions (Vinson 2007). Māori are socially and politically disadvantaged and marginalised in their own land (Durie 1998c). Māori live within a reasonably affluent society, yet are part of a worldwide group of indigenous peoples who have been dispossessed of their lands and resources, and subsequently bear a disproportionate burden of health problems (Voyle and Simmons 1999). Such populations are amongst those most affected by chronic conditions such as diabetes and diabetes-related complications (Ministry of Health 1997; Rochford 2004). In New Zealand diabetes is a serious health concern (Ministry of Health 2000a). The risk factors for diabetes and diabetes-related complications are significantly high for Māori and have severe impacts on Māori causing illness and death (Ministry of Health 2002b).

Diabetes-related complications have major implications for individuals and their families. Such complications affect quality of life including economic viability, which impacts family, services and the health system. For many, this impact begins to occur at an early age (Ministry of Health 2002b).

Foot complications are of particular concern (Ministry of Health 2003n). Diabetes-related foot complications are serious and include diabetic foot disease, Charcot's foot<sup>4</sup>, ulceration and amputation. There is evidence that a high number of diabetes-related amputations are performed on Māori (Thompson, McWilliams et al. 1993; Baxter 2002). Yet the risk of foot complications can be reduced and even prevented if treated appropriately and within a timely manner (Ministry of Health 2003n).

# DIABETES IN NEW ZEALAND

Diabetes is identified as a priority health area within the New Zealand Health Strategy (Baxter 2000; Ministry of Health 2000a; Ministry of Health 2003f). To date it is estimated that 116,000 people have been diagnosed with Type 1 or Type 2 diabetes. Type 2 diabetes generally remains asymptomatic for several years with diagnosis and treatment often delayed. As a consequence, it is estimated that approximately 115,000 New Zealanders remain undiagnosed with type 2 diabetes and a further

<sup>&</sup>lt;sup>3</sup> Chronic condition; See glossary of terms

<sup>&</sup>lt;sup>4</sup> Charcot's foot: A foot disease associated with loss of nervous stimulation to the foot due to diabetes that results in destruction of joints and soft tissue in the foot. Online dictionary http://cancerweb.ncl.ac.uk/cgi-bin/omd?charcot's+foot

300,000 are at risk (Diabetes New Zealand 2007). Diabetes imposes huge costs on health systems and services and for the period 2001/2002 it was estimated that type 2 diabetes cost New Zealand tax payers \$247 million. If services were maintained at the same level to 2021 estimations continue to be calculated at a further one billion dollars per year (PricewaterhouseCoopers 2007).

# Incidence

The incidence of Type 1 Diabetes appears to be increasing both in New Zealand (Ministry of Health 2003i) as well as internationally (Onkamo, Vaananen et al. 1999; Ministry of Health 2003i). Type 1 Diabetes is less common in Māori and Pacific peoples than in New Zealand non-Māori/Pacific peoples (Ministry of Health 2003i). Type 2 is more common in Māori, representing approximately 95% of known diabetes in Māori and Pacific peoples (Ministry of Health 2003k). According to the Waitemata District Health Board (WDHB) (Waitemata District Health Board 2002) the rates for other ethnic minority communities in New Zealand are also likely to be high.

# Prevalence

According to the National Health Committee in 2007, the prevalence of diabetes (and other chronic diseases) in New Zealand continued to increase (National Health Committee 2007). One in every 23 people in New Zealand had been diagnosed with diabetes according to the New Zealand Health Survey 2002/2003. The prevalence of diagnosed diabetes was four times higher in people living in the most deprived areas compared to those living in the least deprived (Waitemata District Health Board 2002; Ministry of Health 2003m).

The prevalence of type 2 diabetes is predicted to increase among Māori by 132% by the year 2011 (Ministry of Health 2003f; Ministry of Health 2003I). A proportion of this increase in prevalence will be the result of aging and other demographic trends such as increase in population size. One third will be a consequence of obesity and physical inactivity being more common (Ministry of Health 2003f).

#### Prevalence in Waitemata

According to the Ministry of Health (Ministry of Health 2005n) there were approximately 13,000 people diagnosed with diabetes who were over the age of 25 years in the Waitemata district in 2004 and about 800 more will develop the condition each year (Waitemata District Health Board 2002; Ministry of Health 2005n). Further, there are estimates that within the Waitemata district approximately 16,000 people will have diabetes by the year 2011 (Ministry of Health 1999c).

A number of characteristics common to different cultural populations contribute to the high prevalence rates of diabetes for marginalised populations including social, political, economic, cultural and environmental factors (Alemu and Lindtjorn 1995; Brown 1998). These factors have been influenced by colonisation, westernisation and acculturation (Rochford 1997; Voyle and Simmons 1999), all of which have affected the health of marginalised populations and their ability to access resources such as quality food, education and appropriate health care. Those populations who have managed to maintain traditional lifestyles have been found to have lower prevalence rates of diabetes. In order for effective strategies for populations at high risk to be implemented, these factors need to be taken into account.

# DIABETES-RELATED FOOT DISEASE AND COMPLICATION

Foot complications in people with diabetes have been found to be associated with social deprivation, poor vision, obesity and foot deformity (National Collaborating Centre for Primary Care 2004). Complications are common in people with diabetes and if not treated appropriately can have devastating effects (Jirkovska, Boucek et al. 2000; Ministry of Health 2003n; National Collaborating Centre for Primary Care 2004; Modawal, Fley et al. 2006).

Diabetic foot disease is the most common cause of hospital admissions in people with diabetes in first world countries (Campbell, Graham et al. 2000). High therapeutic costs and low quality of life caused by lower extremity amputation is the most severe consequence of the condition (Ortegon, Redekop et al. 2004). Un-treated diabetes related foot disease causes pain and can lead to chronic foot ulceration, reduced mobility, lower limb amputation (Ministry of Health 2003f) and premature mortality (World Health Organisation 1995; Apelqvist 2000; Valk, D et al. 2001; Ministry of Health and the New Zealand Guidelines Group 2003).

# Charcot foot

The diabetes related Charcot foot is a major limb-threatening complication (Frykberg 2000) that almost always occurs in those with neuropathy (nerve damage). The presence of neuropathy causes the bones in the foot to become weakened. Weakened bones fracture easily. Pain can often go unnoticed due to loss of sensation. This can lead to severe deformities of the foot and disability. Early diagnosis and treatment is therefore vitally important (ePodiatry.com 2009).

#### Foot ulcers

Foot ulcers are among the most common complications of diabetes (Lavery, Armstrong et al. 2003). Foot ulcers can involve high costs, have the potential to identify those at high risk for amputation, affect patients functional status and well-being, and may be preventable (Reiber, Vileikyte et al. 1999; Patout, Birke et al. 2000). Loss of sensation and high foot stress are the primary causes of foot ulcers (Patout, Birke et al. 2000) and usually involves a break in the protective covering of the skin causing damage to underlying structural tissues (Reiber, Boyko et al. 1995; Reiber, Vileikyte et al. 1999).

Other important factors associated with ulceration include; older age groups, male, particular ethnic groups, longer duration of diabetes, poor vision, renal disease, impaired mobility, smoking, poor footwear, poor nutrition and social deprivation/isolation (Ministry of Health and the New Zealand Guidelines Group 2003). Evidence suggests that appropriate screening and intervention measures such as early detection and effective treatment of foot ulcers are considered to be the best methods of interrupting the pathway of lower extremity amputation (Reiber, Vileikyte et al. 1999; Patout, Birke et al. 2000; Ministry of Health and the New Zealand Guidelines Group 2003; Singh, Armstrong et al. 2005).

Between forty and sixty percent 40-60% (Earp and Ennett 1991; ePodiatry.com 2009)) of all amputations of the lower extremity are performed in patients with diabetes (Adler, Boyko et al. 1999; Apelqvist 2000; Coleman 2000)

Nearly half of all lower extremity amputation involve above or below the knee amputation with the remainder affecting toes or feet (Reiber, Vileikyte et al. 1999). Amputation has been associated with an increased risk of re-amputation of the same extremity (Armstrong, Lavery et al. 1997). More than 85% of these are precipitated by a foot ulcer that has deteriorated to deep infection or gangrene (Apelqvist 2000; Boulton, Kirsner et al. 2004; Lester Reed 2004).

There are a number of demographic risk factors for lower extremity amputation including; age, gender and ethnicity (Coleman 2000; White, Bell et al. 2004). The incidence of lower extremity amputation in diabetes varies widely between different geographical areas, even in the same country, as well as between different ethnic groups within a population (Gujral, McNally et al. 1993; Pollard 1999). In many countries foot complications including lower extremity amputations are often exacerbated by factors such as walking bare foot, inappropriate footwear, lack of knowledge of diabetic foot complications and the socio economic status of patients (Viswanathan, Madhavan et al. 2005).

# Summary

Foot complications and lower extremity amputation can impact severely on people living with diabetes. Physical impacts include reduced mobility and pain. Social impacts include isolation, both emotional and psychological by effecting interpersonal relationships, and economical through reduced employment and high medical costs (Apelqvist 2000; Singh, Armstrong et al. 2005; Diabetes New Zealand 2007). According to Apelqvist and Larsson (Apelqvist 2000) in order to reduce these costs the solution would be to avoid amputation. Effective management including treatment, education and support is required to maintain health and prevent the development of diabetes-related complications. Interventions that are aimed at managing diabetes and preventing complications are significant in determining the long term outcomes of diabetes for individuals, family and health systems (Ministry of Health 2003f). There are steps by the NZ Government and Diabetes organisations to begin to address these issues.

# DIABETES INITIATIVES IN NEW ZEALAND

New Zealand based initiatives have been established to improve the prevention, reduction, treatment and monitoring of diabetes and diabetes-related complications. A growing number of initiatives have been implemented at both national and local levels and are developed and supported by and through Government, DHBs, PHOs, and research and community groups. Initiatives set up have included strategies, tools for screening and monitoring, health promotion, education and new funding streams targeted toward diabetes management. A number of initiatives have been developed with the aim of moving toward more accessible, appropriate and affordable services to high risk populations such as Māori, Asian, and Pacific peoples (Ministry of Health 2002j)

Some of these strategies are:

- The Diabetes Strategy (Controller and Auditor General 2004) Diabetes is one of the 13 health priority gain areas specified in the New Zealand Health Strategy.
- The National Diabetes Research Strategy (NDRS)' The Health Research Council of New Zealand (HRC) has identified diabetes as a research priority (Ministry of Health 2000a).
- Regional Diabetes Registers Diabetes registers have been established across many New Zealand general practices, with a number of practices now using centralised rolls as part of the 'Diabetes Get Checked Programme' (Ministry of Health 2002e; Joshy and Simmons 2007);

- Diabetes Toolkits (Ministry of Health 2003f; Ministry of Health 2003i; Ministry of Health 2003n)
- Local Diabetes Teams (Baxter 2002; Controller and Auditor General 2004)
- The Diabetes Get Checked Programme (Controller and Auditor General 2004; Tomlin, Tilyard et al. 2006)
- Care Plus (Ministry of Health 2004)
- Other initiatives. A number of other locally based initiatives which are based on the government strategies and key priorities mentioned above across new Zealand. Many interventions look at lifestyle interventional approaches (Simmons and Fleming 2000; Murphy, Kordyl et al. 2004) to reduce, prevent, support and manage diabetes and are primarily aimed at Māori and Pacific Island peoples.

# INTERVENTIONS TARGETING FOOT COMPLICATIONS

With the appropriate intervention, management and care, it is believed that lower limb amputation could potentially be delayed or even prevented with appropriate management and care (Armstrong, Lavery et al. 1997; Ministry of Health 2003i; National Collaborating Centre for Primary Care 2004).

Subsequently, the quality of foot care programmes is an important factor. Such foot care programmes could include: foot care education at diagnosis of diabetes, sound advice and assistance in primary care, as well as the involvement of podiatry and other specialised teams (Ministry of Health 2003i).

Foot care programmes that have been 'successful' involve a number of components. These components include: motivated patients and an effective medical system (Singh, Armstrong et al. 2005): Increased awareness of foot complications (White, Bell et al. 2004); models of foot care that are varied according to local need and populations and the specialist skills available (Winocour, Morgan et al. 2002; White, Bell et al. 2004). Further, age, gender ethnicity, body mass index, control of blood glucose levels, degree of self monitoring, duration of diabetes and health insurance coverage are all taken into account (White, Bell et al. 2004).

There are a wide range of potential preventative, treatment and intervention strategies. These include screening, education, multidisciplinary approaches, podiatry and foot clinics, special footwear, guidelines and protocols.

# Screening

Screening is a commonly used method to assess patients for diabetes and in particular diabetesrelated foot complications. Risks for diabetes foot related pathology are assessed and intervention types and frequency designed according to the assessment (Singh, Armstrong et al. 2005). According to Jirkovska and colleagues (Jirkovska, Boucek et al. 2000) improved screening and the identification of high risk individuals and appropriate risk directed treatment at the primary care level has been identified as the most effective way of reducing a large number of ulcerations and preventable diabetic related lower extremity amputations (Armstrong, Lavery et al. 1997).

There are a number of different types of screening available including the Semmes-Weinstein Monofilament, which is widely advocated as an effective non-invasive screening tool in the detection of foot neuropathy (Jirkovska, Boucek et al. 2000; Pham, Armstrong et al. 2000; Armstrong, Lipsky et al. 2006; Modawal, Fley et al. 2006). Dermal Thermometry is used to indicate when treatment has

failed (Armstrong, Lavery et al. 2004). Such medical screening devices are useful tools. However, most important is self management where possible.

## Self management

One of the most important ways in which problems with a health condition can be avoided is through early identification of potential problems. Daily self examination is the first step in prevention (Coleman 2000). Identifying problems early occurs through awareness of the condition and its impact, attention to individual triggers, and early recognition of warning signs by the patient themselves (Russell 2005). Knowing there is a potential problem, however, must always occur in tandem with knowing how to act should such symptoms occur, and knowing who to ask for help, and how to ask for that help so that it is timely, effective and preventive (Pomare, Tutengaehe et al. 1992; Russell and Browne 2005). Through preventive action and self monitoring, many foot problems could be avoided (Lavery, Higgins et al. 2007).

Self management is said to consist of a number of components. According to Lorig and Holman (Lorig and Holman 2003) these include medical, role and emotion management. Medical management includes taking medication, being consistent with recommended diets, checking feet, applying creams, using orthotics when prescribed. Role management involves maintaining and changing behaviour or life roles such as exercise, diet or employment. Emotional management involves dealing with the emotions associated with the condition such as anger, fear and frustration, not being able to fulfil what one believes in their own role. It is crucial that assistance is holistic and not just focused on one aspect of a person's life (Corbin 1998).

Yet, as noted above, people with diabetes who are at high risk for foot ulceration may be limited in their self care abilities due to other diabetes-associated factors such as poor vision, obesity, and limited mobility (Chincholikar and Pal 2002; Singh, Armstrong et al. 2005). Subsequently, it is important that those around them are able to assist when needed.

# Education

Studies have shown that specialised education programmes and health promotion have been associated with improved foot care knowledge, self care behaviour and reduced risk of amputation (Campbell, Graham et al. 2000; Corbett 2003). Education has been shown to be a critical component of self management (Day 2000; Corbett 2003). On the other hand, a lack of education about diabetes foot care has been shown to be associated with lower extremity amputation (Mayfield, Reiber et al. 1998; White, Bell et al. 2004).

Educational programmes have been found to work best when they include certain components. These are: information that is simple, age, culture and language appropriate, relevant, consistent and repeated (Apelqvist 2000; Watson, Obersteller et al. 2000; Viswanathan, Madhavan et al. 2005). Education can be focused on people living with diabetes, whānau/families, partners or health professionals.

#### Patient education

Patient education improves both (short) term knowledge and prevention of foot ulcers and amputations in people with diabetes (Campbell, Graham et al. 2000; White, Bell et al. 2004; Singh, Armstrong et al. 2005). Education is also important to patient's being able to identify their own foot lesions.

However, some authors suggest that people may still not fully understand how to properly provide self care despite education (Plummer and Albert 1995; Corbett 2003). Nevertheless brief educational interventions individualised according to patient needs have been shown to improve patient knowledge and confidence and improve foot care practices (Plummer and Albert 1995; Corbett 2003). Foot care education of people with diabetes is also believed to increase podiatry attendance (Campbell, Graham et al. 2000). In addition, educated patients will more likely ask for a foot examination while attending a medical clinic (Pollard 1999).

#### Whānau/Family education

People who live with diabetes are often unaware of their own ulcers due to immobility, visual impairment, obesity, and other related factors (Thomson and Masson 1992). However, family/whānau, relatives and health care staff often identify an ulcer before a person living with diabetes recognise it themselves (Macfarlane and Jeffcoate 1997; Apelqvist 2000). Although few studies highlight the need for family education, some authors suggest that it may be beneficial to involve family members in the assessment and education of patient self care practices (Lavery, Armstrong et al. 2007).

#### Health professional education

Education of health care providers about how to identify foot pathology can have significant effects on reducing rates of foot ulceration and amputations (Pollard 1999). Several studies indicate the importance of health care staff education with regard to early recognition of potential risks of foot complications (Pollard 1999; Apelqvist 2000; White, Bell et al. 2004). Yet researchers have found that health care providers more frequently miss problems with patient feet than the patients themselves (Apelqvist 2000) Nonetheless, there are a number of difficulties to ensuring health care provider education, including clinician values and educational experience, as well as health care service limitations.

According to White et al (White, Bell et al. 2004) education of both patients and health care providers is important to enable dissemination of information in the early years after diagnosis.

#### Multi disciplinary team approach

Referral to appropriate specialised services and clinicians supports prevention of foot ulcers and complications due to early recognition of high risk patients (Patout, Birke et al. 2000; Muller, de Grauw et al. 2002; White, Bell et al. 2004). Assistance from a range of professionals is important to delivering effective, coordinated care that is most convenient for people with diabetes (Patout, Birke et al. 2000; U.S. Department of Health and Human Services 2000; Meltzer, Pels et al. 2002; Muller, de Grauw et al. 2002; Winocour, Morgan et al. 2002). JoInterview specialised services have also been documented to lead to lower foot ulceration and amputation rates by successfully integrating a medical podiatric surgical approach (Winocour, Morgan et al. 2002).

A multidisciplinary foot care team approach that involves a preventative strategy, patient and staff education and multi-factorial treatment of foot ulcers has been shown to improve the speed of ulcer healing, decrease ulcer reoccurrence and amputation rates in people with diabetes with high risk feet and has been shown to be cost effective (Ministry of Health and the New Zealand Guidelines Group 2003).

#### Podiatrists and foot clinics

Podiatrists play an essential role in supervising education programmes for people with diabetes and delivering interventions for individuals with correctable foot conditions and high risk feet. The value of regular podiatry foot examinations and access to (high quality) foot care in the prevention of ulceration in lower limb amputation is well established (Pollard 1999). Podiatry assistance is believed to be able to reduce the frequency of lower leg amputation significantly (International Working Group on the Diabetic Foot 1999)

Education to patients given by a podiatrist has demonstrated a positive effect on minor foot problems after a relatively short follow up (New Zealand Guidelines Group 2001; Ministry of Health and the New Zealand Guidelines Group 2003).

Access to a podiatrist reduces the number and size of foot calluses and improves self care (Ronnemaa, Hamalainen et al. 1997). Specialty diabetic foot clinics have been shown to be successful in both healing ulcers and reducing the incidence of ulceration and amputation in high risk patients (Coleman 2000; Singh, Armstrong et al. 2005; Lavery, Armstrong et al. 2007). Many of such clinics provide insoles, foot specific education as well as advanced clinical care.

Podiatrists are also known for their skill and influence when promoting foot care skills to primary care clinicians (Ministry of Health 2003i). Part of the information provided to patients is around what footwear to choose for the best foot care.

#### Footwear

Studies have shown that protective footwear when available and used can prevent re-ulceration in 60-85% of patients with previous ulcers (Apelqvist 2000). Footwear designed for people with diabetes protects high risk feet and helps lead to fewer complications (Armstrong, Abu-Rumman et al. 2001). People with diabetic foot disease are often advised to wear high quality cushion-soled running or sports shoes rather than ordinary shoes. Dependent on the severity and risk of complication patients may also be encouraged to wear custom built footwear or othotic insoles to reduce callus severity and ulcer reoccurrence (Ministry of Health and the New Zealand Guidelines Group 2003).

Choosing not to wear specialised footwear is often a significant problem, and is mainly associated with cost, access (Apelqvist 2000; Ministry of Health and the New Zealand Guidelines Group 2003) and cultural factors. As a consequence many patients often resort to wearing conventional, non prescribed and often unsuitable footwear or bare feet (Ministry of Health and the New Zealand Guidelines Group 2003; Viswanathan, Madhavan et al. 2005).

# PEER TO PEER SUPPORT

Since the 1960s there have been peer-to-peer support programmes for people living with diabetes in New Zealand. According to Simmons and colleagues in 2009 (Simmons, Voyle et al. 2009) peer support programmes appear to be successful, in demand and to be of benefit in primary prevention. However, evaluation has only been quantitative, and further data is required to demonstrate efficacy of the programmes according to participant perspectives.

# SPECIALISED FOOT PATHOLOGY PREVENTION PROGRAMMES

A number of prevention programmes have been trialled with great success (Patout, Birke et al. 2000; U.S. Department of Health and Human Services 2000). Programmes that have been implemented have shown large improvements in foot outcomes in high risk populations (Patout, Birke et al. 2000).

Patout and colleagues, for instance, found that by improving access and reducing disparities in foot care services showed significant improvements after a one year enrolment. Improvements were attributed to the consistent application of appropriate preventative care and treatment as well as careful follow up (Patout, Birke et al. 2000).

The critical success factors of prevention programmes appear to be: consistency in application, appropriateness of care, treatment and intense follow up. However, there is no consistent and overarching approach to prevention.

# ACCESS TO SERVICES

For the purposes of this literature review, 'access' was defined according to a range of literature (Bierman, Silverman et al. 1998; Baxter 2002; Cormack, Ratima et al. 2005). Thus the concept of 'access' incorporated:

- patient access to and access through health care services
- gaining entry to the healthcare system
- navigating through the healthcare system
- ability of providers and the healthcare system to understand and address specific needs

Easy access to health services in an appropriate and timely manner is an important factor in managing and treating diabetes-related complications (Bierman, Silverman et al. 1998; Baxter 2002; Winocour, Morgan et al. 2002; Ministry of Health 2003f; Cormack, Ratima et al. 2005).

Family GPs frequently play a central role in the assessment and treatment of diabetes treated complications (Mayfield, Reiber et al. 1998; Muller, de Grauw et al. 2002; White, Bell et al. 2004). GPs are able to assess patient risk level factors, and enhance patient education (Mayfield, Reiber et al. 1998; Rith-Najarian, Branchaud et al. 1998; White, Bell et al. 2004)while making timely referrals to specialist services that are in place (Ministry of Health 2003n) such as hospital and podiatry/foot treatment clinics (Masson, Angle et al. 1989; Mayfield, Reiber et al. 1998; Muller, de Grauw et al. 2002).

Nonetheless, some have found that services that are established are at times inadequate in terms of prevention (Ewald, Patel et al. 2000). Barriers to access, failure to identify those at risk and inadequate and untimely referrals to specialist reduce the value of services in the prevention and/or delay of lower limb amputations.

On the other hand, the provision of various health services and specialised treatment clinics does not mean patients will access them (Ministry of Health 2003n). Many people who are diagnosed with diabetes do not reliably access treatment available to them (Baxter 2002) including those at highest risk of diabetes complications. Further, when people do access such services, there is often no guarantee of accurate or equal treatment (Penney, McCreanor et al. 2006). The Ministry of Health state that services need to be technically excellent and effective in reaching those most in need of such services (Ministry of Health 2003f).

#### **Guidelines and protocols**

Minimal research about whether locally established guidelines and protocols reduce length of hospital stay and major complication rates in the literature reviewed (Rith-Najarian, Branchaud et al. 1998; Crane and Werber 1999; Ministry of Health and New Zealand Guidelines Group 2003p). There is evidence however, to suggest that regular foot checks undertaken according to clinical guidelines can reduce the risk of ulceration and amputation (Ministry of Health 2003f), identify those most at risk and provide appropriate referral to specialist services (Griffin and Kinmonth 2001; Ministry of Health and New Zealand Guidelines Group 2003p).

#### Summary

A range of interventions aimed at reducing foot complications have been reported and proven to achieve successful outcomes especially in non-Māori populations. Equally crucial is that interventions are designed to meet those in most need of them and that services ensure easy access, availability of service, affordability and timeliness. Nonetheless, cultural impacts indicate that Māori (and other indigenous populations) may need intervention that is tailored to their needs.

#### **CULTURALLY INNOVATIVE INTERVENTIONS - KEY COMPONENTS**

Innovative interventions have been developed and implemented in a range of countries. Such interventions are aimed at chronic disease and improving the health of high risk populations and include educational, promotional and lifestyle components and support the prevention, reduction, control and management of chronic conditions. Although populations themselves differ, many interventions share a number of key cultural components that have been successful in reducing chronic conditions for marginalised populations.

#### **Multi-faceted approaches**

A number of approaches recognised the need to take into consideration that minority populations and indigenous peoples are not homogenous therefore approaches need to be varied and multi-faceted if they are to be successful in achieving the desired outcomes (Goslar, Macera et al. 1997; Ministry of Health and New Zealand Guidelines Group 2003p; Bloche 2004; Whittemore 2007). Watson and colleagues (Watson, Obersteller et al. 2000) note that effective education requires designing it for the group it is aimed at while acknowledging the diversity of populations and within groups. Variation must

take into account the needs of local populations and the specialist skills available (Winocour, Morgan et al. 2002). Community consultation is also crucial.

#### Community consultation

Establishing partnerships, close relationships and linkages with the community where the programme is targeted is vital. Acknowledgment of community members by involving them on advisory boards, as members of research teams and as community workers from initiation to completion of programme ensures successful outcomes and sets up for future affiliations for ongoing or prospective programmes (Brown 1998; Simmons and Voyle 2003).

# Staffing

The number, level and cultural competency of staff members involved in initiatives were seen as important factors. Programmes frequently ensure a mixture of qualified, experienced staff with health, community and cultural backgrounds. Many initiatives support and promote the use of interdisciplinary teams and take into account factors relating to cultural, communication, family/whānau and patient empowerment (Simmons 1999; Murphy, Kordyl et al. 2004; Tamwoy, Haswell-Elkins et al. 2004). Bilingual staff members of the same culture as the programme participants is viewed as ideal. Many programmes using this approach recruit participants successfully (Goslar and al 2000; Hawthorne 2001)..

Another staffing approach is to conduct 'train the trainer; programmes. Bilingual health professionals and local residents or 'generalist health', 'link' or 'lay' workers from the community are trained to teach the intervention. This approach covers language and cultural barriers that might interfere with the programme success whilst it also addresses to some extent workforce capacity issues where culturally appropriate worker numbers maybe scarce (Brown 1998; Hawthorne 2001; Azizi, Gouya et al. 2003). Active involvement of teachers within the learning environment has also been found helpful (Simmons and Fleming 2000; Murphy, Kordyl et al. 2004). In this way, trust and relationship can be built.

#### Venue

The venue where programmes are delivered is found to be critical to participation (Brown 1998; Simmons and Fleming 2000; Tamwoy, Haswell-Elkins et al. 2004). Very few interventions that were reviewed were delivered in a hospital or clinical setting (Brown 1998). For Māori the hospital setting is seen as a barrier to participation (Tuttle 2001; Murphy, McAuley et al. 2003).

#### Materials and resources

Materials and resources used were often translated into the first language of the participating community as well as English and put into very simple terminology (Watson, Obersteller et al. 2000). Audio (e.g. tapes) and/or visual materials (e.g. videos, DVDs, computer software) were also translated and colorful pictures appropriate to the culture were incorporated as part of many programmes (Voyle and Simmons 1999; Watson, Obersteller et al. 2000; Hawthorne 2001; Azizi, Gouya et al. 2003; Tracey and Bramley 2003). One study highlighted the use of focus groups to determine the type of medium, language and content of a diabetes educational resource used at targeting Aboriginal and Torres Strait Islanders (Watson, Obersteller et al. 2000). There is widespread agreement that

educational tools and resources specifically designed for populations, in particular for indigenous or minority groups who are at high risk of foot complications, are very limited in regard (Watson, Obersteller et al. 2000).

#### Native language usage

Providing educational sessions in the native language of participants was a common strategy to ensure cultural relevance. In some cases interventions were delivered in both English and the native language or in English by or with a bilingual support or community worker (Whittemore 2007). Use of interpreters were also mentioned, However problems associated with interpreters were the need for prior arrangement, cost, limited geographic coverage by interpreters as well as limited availability (Hawthorne 2001; Tracey and Bramley 2003).

#### Duration of programme

Although programmes failed to report on whether timing of programmes were a significant factor in successful outcomes, most were delivered between 6 - 15 weeks. One study involving African Americans did note differences in outcomes when lower educational hours were given compared to non-Hispanic Whites (Cowie and Harris 1997).

#### Intense support

Two programmes reviewed identified the need for intense support for many participants in all aspects of the programme, particularly pertaining to the individualised components. Staff were said to provide support by telephone, face to face and home visiting when necessary to ensure questions and queries were answered for individuals and their family members (Murphy, McAuley et al. 2003; Tamwoy, Haswell-Elkins et al. 2004).

#### Delivery

Programmes ranged in delivery from providing nurse case management, basic diabetes education, foot care and complication awareness, and lifestyle programmes incorporating physical activity, self care management, dietary information and education. Many programmes used collective group sessions for education, physical activity and food preparation. Individual sessions were also held for collection of baseline data such as weight, height, BMI as well as one on one education and individualised treatment, food and physical activity plans. Some studies found that patients participated more and showed better commitment to their individual programmes when incorporated as part of group sessions (Philis-Tsimikas and Walker 2001; Murphy, McAuley et al. 2003).

Some innovations in delivery were identified in the literature reviewed. Intensive control clinics within health care practices, supported by a practice nurse, specialist nurse and an Asian link worker (Chow, So et al. 2003; Raymond, O;Hare et al. 2003) were established. Other programmes were delivered by a multidisciplinary team of health professionals and based on the enhanced model of primary health care. The enhanced model required that holistic services are delivered. These services include individual visits to each island community on a regular basis using a simple paper based recall system. In this instance, the community was involved along with a team of local GPs at all steps of health care (Watson, Obersteller et al. 2000). (no results of these studies)

# **Cultural foods**

Important emphasis was placed on diet across many interventions incorporating the use of traditional cultural foods in class cooking sessions, pamphlets and education sessions (Simmons 1999; Hawthorne 2001). An overwhelming theme in such programmes was that participants give up their traditional cultural foods in order to be healthy. Information about how, instead, to modify ingredients or ways of cooking to incorporate traditional foods in a healthy way were discussed (Alcozer 1998; Drewniowski and Spector 2004; Murphy, Kordyl et al. 2004; Dea, Rowley et al. 2007). In contract, incorporating traditional foods into regimes in two programmes aided in more commitment and better outcomes (Murphy, McAuley et al. 2003).

# Family

Participation of family members was found to be an important aspect to programme success. It was found that family members added to the support of changing lifestyle behaviours, education and understanding. The majority of programmes acknowledged this by welcoming family members to attend education, screening, monitoring and cooking sessions or by including them in consultation when visiting participants in their homes. (Hawthorne 2001; Murphy, Kordyl et al. 2004; Tamwoy, Haswell-Elkins et al. 2004).

# Literacy

Low levels of literacy were a common issue identified across cultures and initiatives. A number of interventions dealt with low levels of literacy by using colorful visual aids, story-telling, interpreters and the use of bilingual support workers as well as appropriate props (Hawthorne 2001; Fanning, Selwyn et al. 2004). However, this need is often not take into account when programmes are designed and delivered.

#### Funding and resource allocation

Adequate funding for resources was also found to be a common theme. Having material translated into another language or making them at the very least culturally adequate was said to be expensive. Some programme staff used their own networks to find or make resources (Rowley, Gault et al. 2000). In some cases workers borrowed equipment in order to implement components of a planned intervention. The Indian Health Service in the USA, however, showed that where resource allocation is increased, significant improvements in glycaemic control and in other intermediate clinical outcomes can be achieved (Rith-Najarian, Branchaud et al. 1998).

#### Other cultural considerations

Other cultural factors were said to be taken into consideration by some education programmes and interventions (e.g. religion, beliefs, health perspectives, music) when the literature about diabetes related foot pathology was reviewed. This was particularly emphasised in a programme involving British-Pakistani women where they were prohibited to attend clinics on certain days, could not be seen to be alone in public, or with a member of the opposite sex (Hawthorne 2001; Hawthorne 2001). The intervention implemented that targeted this population ensured these cultural factors were taken into consideration.

#### SUMMARY

Specific interventions aimed at improved foot care such as patient education, specific diabetic foot screening and access to clinics can reduce rates of foot ulceration and ultimately amputations. A number of cultural components that have been implemented into interventions have been presented that highlight similarities between many cultural groups. The value of such approaches increases significantly when specifically designed for the targeted population. Incorporating specific cultural approaches such as language, food, and family are vital to ensure intervention success. Specifically and culturally innovative interventions not only benefit those involved in a programme, but will also be of advantage to other populations, while reducing the burden of health system costs.

# MAORI SPECIFIC INTERVENTIONS

Current disparities in diabetes morbidity and mortality including diabetes-related foot complications indicate that conventional approaches for Māori are currently insufficient. Innovative approaches are needed that are more user-friendly by those who feel alienated or uninspired by what is currently available (Simmons and Voyle 2003). It is well reported that many of the diseases that affect Maori are preventable and /or manageable (Sporle and Koea 2004; Ellison-Loschmann and Pierce 2006). Yet research indicates disparities in treatment provision (Sadler, McCowan et al. 2002) that indicate Māori receive care less often and also receive a lower quality standard of care when it is received.

Information from one author suggests that disparities may in part be due to the failure of health services to facilitate the management of chronic disease through the provision of culturally appropriate programmes (Durie 1998). Cormack et al (Cormack, Ratima et al. 2005) noted that there were a lack of specifically designed services to meet the needs of Maori. For instance, there is limited evidence of the resources being readily available for kaupapa Māori interventions including Māori healing e.g. mirimiri (massage) and rongoa (Māori traditional medicines) as well as Māori-specific services or service components, integrating Māori expertise and advice, locating services in Māori settings, and incorporating te reo Māori (Māori language) while also addressing institutionalised racism.

Although there are very few Māori-specific interventions reported in this literature compared to conventional interventions, there are nonetheless some that continue to be implemented successfully. While many intervention components share a number of commonalities with other cultures there are specific elements of interventions that are unique to Māori. These are related to consultation, programme design, promotion and recruitment, cultural foods, physical activity, and language usage. Some components of programmes that have been shown to not work with Maori are also identified.

#### Lower limb complication control

It is believed that many of the problems with feet that are related to diabetes among Maori could be prevented if Māori received appropriate preventative care (Ministry of Health 2004u). Such care is said to include improved foot screening, early intervention, continual maintenance and referral at appropriate times (Ministry of Health 2004u).

However, Māori patterns of health service use differ from those of non-Māori. Māori have low access to and use of primary health care services and limited on-going care (Pomare, Keefe-Ormsby et al. 1995; Malcolm 1996; Simmons and Fleming 2000). Further, Ewald and colleagues (Ewald, Patel et al. 2000) have expressed concerns that there are inadequate services for the prevention and care of diabetic foot complications among Māori.

The potential benefits of foot pathology intervention has been demonstrated by the Wellington Independent Practice Association (WIPA) Diabetes Podiatry Community Project initiated in 2002 (Wellington Independent Practice Association 2003). WIPA established 11 community podiatry clinics for patients diagnosed with diabetes who were deemed at-risk of developing foot complications. The WIPA Annual Report (Wellington Independent Practice Association 2003) notes a reduction in amputations in the region covered by the intervention.

Māori may require specific foot care (Ministry of Health and the New Zealand Guidelines Group 2003). Yet there is little information available that is from Māori perspectives and also robust and research driven and identifies what such specific foot care would consist of, and how it would be provided. This is surprising given that diabetes prevention and research for Māori are described as priorities in national health documents such as New Zealand Health Strategy, He Korowai Oranga (Ministry of Health 2002b).

There is a need for Māori specific information to enable an evidence-based approach to addressing the disproportionate impact of diabetes-related lower limb complications among Māori. Further new knowledge developed through the proposed research is also likely to have wider application to other indigenous peoples.

# Consultation

Similar to other cultures, the consultation and approval process with key Māori leaders and local Māori in the first instance is crucial in order to get community buy in for the programme. Consultation continued through-out the duration of the programme and beyond is essential to participation and successful outcomes (Simmons and Fleming 2000; Murphy, Kordyl et al. 2004). Consultation is also an ethical requirement of research in New Zealand (Health Research Council of New Zealand 2008)

# Programme design

Ensuring that the programme is specifically designed for the targeted community group has also been vital (Simmons and Voyle 2003). As previously mentioned Māori are not an homogenous group. Māori differ in many ways, emerging from different tribal groups, use of different words and dialects and have diverse beliefs and behaviours. For example, a programme developed and designed in consultation with Māori from Dunedin and implemented with Māori in Gisborne had difficulties in gaining adequate numbers of participants as the programme was not locally designed and thus semi inappropriate (Tuttle 2001).

Another important part of programme design is ensuring a kaupapa Māori approach, that is ensuring the programme where possible is Māori led, Māori driven using an 'about Māori, for Māori by Māori' approach where Māori are at the centre and ensuring it benefits Māori. Although the ideal programme targeted at Māori would be staffed to capacity using all ranges of Māori health professional skill, it is recognised that due to a lack of an adequate Māori health workforce, a number of successful approaches have incorporated non-Māori staff combined with Māori leadership. Some have overcome this difficulty. For instance, a programme introduced non-Māori members of their team to the targeted

community in the initial stages of consultation and supported them to attend a total immersion Māori language course (Murphy, McAuley et al. 2003).

# Programme promotion and recruitment

This validates the importance of the consultation process as local communities feel part of a team. Once accepted and trusted, a programme will be promoted by local Māori and members of a research study who know their community well will undertake to promote it to other members of the same society (Murphy, McAuley et al. 2003). Promotion of the programme if successful and appropriate will extend to other parts of society and may be incorporated within other avenues. The use of local newspapers, notice board and community groups can aso be used with community permission for promotion and recruitment of participants.

# Cultural foods

Food is an important part of Māori society not only for physical needs but also social (e.g. welcoming visitors) therefore the incorporation of traditional foods such as seafood, puha, shell fish, mutton bird, nuts, seeds and grains into specific programmes is important (Murphy, McAuley et al. 2003).

# Physical activity

When physical activity programmes are planned it is essential to remember a number of elements that are important or necessary to Māori participation in addition to the above issues. These include cost (Simmons and Fleming 2000; Murphy, Kordyl et al. 2004), easy incorporation in the home and community and various cultural activities such as kapahaka (Māori cultural dance) and waka ama (paddling). One programme that initiated water based activities for instance, obtained high participation rates and success due to privacy of the pool and flexibility of swimming attire (Murphy, McAuley et al. 2003).

# Māori language

Māori language that is incorporated into different tools such as pamphlets, newsletters, information sheets and consent forms were found to be successful in attracting Māori to read and use them. As well it was found that when Māori words were used within programme sessions high participation and consistent retention rates were noticeable (Tracey and Bramley 2003; Controller and Auditor General 2007).

#### Unsuccessful intervention elements

In contrast to the above discussion, there are also elements that contribute to the failure of interventions in particular those interventions targeted at Māori as outlined by Tuttle (Tuttle 2001). Tuttle indicates some of these:

- Lack of cultural competency to deal with Māori population
- Over generalizing regarding the application of a research model
- Lack of collaboration and consultation with Māori communities
- Lack of Māori cultural knowledge
- Proposals based primarily of health statistics and needs analysis opposed to being incorporated alongside local community knowledge and expertise.

- Assuming Māori are homogenous
- Lack of community/tribal involvement from the initial stages (input sought only when needed)
- Māori interviewers not trained and supported adequately and appropriately and therefore lacked confidence and comfort to ask a number of pertinent health questions critical to the research
- Recruitment undertaken by inappropriate non-Māori health staff (hospital or general practice staff)
- Programme not culturally appropriate

# Summary

Māori share many commonalities with other cultures and therefore interventions to address diabetes and diabetes-related foot complications may also have mutual components. Some elements however are unique to Māori and need to be seriously taken into consideration when designing and implementing programmes about, for and with Māori. Partnership, consultations, respect, involvement throughout the entire programme or research is all crucial to activities, as is adherence to the Treaty of Waitangi and ethical guidelines. Acknowledging what is unique to Māori will support successful outcomes for service providers, researchers, community and the healthcare system. Equally crucial is to gain understanding and awareness from failed research and interventions in order to move forward in a positive manner.

# DISCUSSION AND CONCLUSION

Diabetes has impacted health worldwide, with increasing concern for indigenous, ethnic, and marginalised populations as the affect of inequality becomes more known and understood. The impacts of colonisation, westernisation and acculturation differ to varying degrees across cultures. However a common consequence has been the negative impact these social and political processes have created in regards to the health of vulnerable populations.

The literature review highlighted a broad range of issues that exist in relation to diabetes and diabetes care. Diabetes care and treatment require careful consideration when emphasising specific areas such as food. In managing diabetes there tends to be a particular focus on eliminating certain foods and introducing others. For many people the message tends to be received as a case of giving up what is bad for something that is perceived to be good. Many health professionals are sending out over riding and often over whelming messages that in order to be healthy one must reject traditional cultural foods (which are bad) and replace them with other most often foreign type foods (which are good). Often regimes are strict and offer little flexibility or alternative options and there have been experiences of regimes being offered or introduced by health professionals in condescending and often angry tones particularly when the routine is not adhered to. Further, according to Alcozer (Alcozer 1998) to inform people to give away their cultural foods is insensitive and an inaccurate message.

The issue for those of certain ethnicities of being labeled 'non compliant' in regard to accessing health care, medication or adhering to regimes is commonly reported both in research and in the health care arena. The negative connotations associated with this label shows failure on behalf of those working in the health system in understanding the barriers many vulnerable populations may face when being put in these situations (Baxter 2002). Brown (Brown 1998) states that few Americans adhere to

recommended guidelines and a study involving nine experts with long standing type 1 diabetes reported that they commonly made decisions about their diabetes that contradicted prescribed recommendations stating that recommendations were neither helpful nor realistic (Paterson and Sloan 1994). According to Simmons (1999) many normal adults find it difficult to adhere to regimes and in order for people to change a behaviour there needs to be agreement, negotiation, and the goal or task needs to be attainable as well as the fact it needs to be a priority for the patient in order for them to make a change. For many marginalised groups recommendations prescribed to them may seem unrealistic and inappropriate with some going against cultural norms and or being put across in a language that they fail to understand (e.g. English and the use of medical terminology) (Brown, 1998). Health professionals should take the needs of the patient, culture and cultural beliefs into account when recommending specific treatments.

# Māori

Of particular concern and pertinent to the review is the impact and devastating affects of diabetes and diabetes-related foot complications on Māori. Access to services for Māori is a significant on-going issue with similar associations of non compliance facing other minority groups. Significant barriers and contributing factors have been identified throughout the review and according to Baxter (Baxter 2002) there is no one solution that will address these issues for all Māori due to the diversity of lives, different impacts of disease and varying locations in which Māori live. What will make a difference are strategies and interventions that take into account the marginalised position of Māori, impact of determinants and culturally innovative approaches that are being developed and implemented across the different sectors (e.g. education and health). Inter-sectoral approaches will aid in the provision to support the growth of a culturally competent workforce (Ratima, Brown et al. 2007), as well as avenues to develop and design culturally appropriate interventions.

#### National and local diabetes initiatives

New Zealand faces many issues in regard to the impact of diabetes and the effects on the population. New Zealand based initiatives recognize the impact of diabetes as a priority health issue highlighting key objectives needed in order to achieve the desired outcomes. Initiatives have been set in place at both national and local levels with many local based interventions focusing on the impact of diabetes on Māori. These initiatives may work remarkably well for the mainstream population but can take considerable time to implement and on-going evaluation is needed in order to determine whether they are appropriate in reaching high risk populations including Māori. Many successful local initiatives set up to target Māori are particularly important but are usually time limited, lowly resourced and only allow for a certain number of participants. These and other on-going issues need to be addressed if positive outcomes for Māori are going to be achieved. Whilst New Zealand recognizes the importance of interventions aimed at diabetes there needs to be more emphasis on strategies that deal with associated complications. The review highlighted that the Diabetes Get Checked Programme and the Management of Type 2 Diabetes Guidelines are the only national strategies that make reference to relevant interventions in regard to assessment and reduction of foot complications.

#### Interventions

Interventions pertaining to foot complications have been highlighted in the review with most immersing the patient in different treatments, with different specialists at different health care locations. Again this may appeal to the mainstream population but evidence suggests that for marginalised populations, interventions such as these can pose barriers to accessing appropriate health care (Crengle 2000; Cormack, Ratima et al. 2005)

## Education

Education emerged as the most commonly used intervention from the literature for prevention, screening, and management of foot complications. The literature revealed not only was education important for the patient but for family members and health professionals alike. Although the majority of educational literature highlighted significant reductions in various foot associated complications, Valk, Kriegsman and Assendelfi (Valk, D et al. 2001) warn caution on interpreting the validity of many studies toward patient education due to the need for further high quality research.

Education and empowerment were shown to be important factors in the self management process where patients take the role of caring for themselves. Self management becomes extremely difficult if the patient has not had adequate and appropriate education and/or support to do so, does not believe they are capable or in fact that it is even their role to be undertaking self management tasks.

#### Models that underpin self management interventions

Whilst the review primarily focused on interventions for foot complications, it is important to discuss specific international models that underpin a number of self management interventions implemented within the Waitemata district. Models such as EPIC (Empowering people in communities), Flinders and the Stanford Model use a number of strategies including; empowerment, problem definition, goal setting, care planning and review to promote behavioral changes in individuals, communities and health providers in order to better manage chronic conditions such as diabetes. They share similar aims which are to raise the quality of life for people living with chronic disease, improve the effective use of the health care system by people with chronic conditions; and enable individuals, families and health care professionals to work together in the management of chronic conditions. The models provide an educational component which takes into consideration cultural aspects (different cultures), environmental factors (living in urban and rural locations), and they have the ability to be used across different areas of health by clinicians (mental health, cancer, diabetes). These models are currently being used within several PHOs with high success rates.

#### Multidisciplinary team

The importance of a multi-disciplinary team was revealed in literature as successfully and significantly reducing the risk of foot complications. Although many interventions recommend this approach, it is used to varying degrees across different countries. There seems to be no universal definition of a multidisciplinary foot care team however, common components have been found to consist of physician, podiatrist, and may include a specialist nurse, orthotist and surgeon or access to a surgeon (Ministry of Health and New Zealand Guidelines Group 2003p). It is also important to consider that some individuals may find a multidisciplinary team approach overwhelming especially when patients

are repeating the same information, therefore a multidisciplinary team needs to be well managed to ensure positive outcomes for patients.

# **Podiatric services**

Referral to a podiatrist is also a successful intervention in prevention of foot complications and where possible it is recommended at the very least that a patient be under podiatrist care. Consideration needs to given to the fact that a podiatrist is not always available and accessible and where there is availability may not always be affordable. In 2001 there were 240 podiatrists and only 1.6 of them were identified as Māori (The Health Workforce Advisory Committee 2002). There is a growing need for podiatrists and in particular Maori podiatrists given that Maori are at high risk of foot complications and amputations (Thompson, McWilliams et al. 1993; Baxter 2002). Concerns have been noted in regard to funding for public podiatry and that it often does not correlate closely with lower limb amputation rates and there is a suggestion that simply increasing funding for podiatry appointments may not reduce the number of diabetic amputations (Ministry of Health 2003n). Funding for podiatry services can be accessed under a few schemes for example Care Plus and regular foot examination and foot screening is commonly identified as the best way to avoid amputation.

# Access to services

Access to a number of interventions for patients includes the necessity to access health care services. Evidence from the literature shows that the under utilization of primary care services by Maori and other low income New Zealanders (Malcolm 1996) contribute to the disproportionately high mortality (Simmons 1999). Evidence also suggests that people from lower socio-economic groups face a number of barriers to accessing health care services (Dovey, Tilyard et al. 1992; Comari and DeBoer 1995; Gribben 1999; Penney, McCreanor et al. 2006) and that ethnicity, gender and social-economic position are frequently associated with differential health care treatment (Kriegar and Sidney 1996; Mayberry, Mili et al. 2000; Ministry of Health 2001f; Geiger 2003; Kriegar 2003; Penney, McCreanor et al. 2006) including receipt of lower guality of care (Brown, Gerzoff et al. 2003).

# Culturally innovative interventions

Literature reveals that delivery of care to minority populations can be complicated by a number of issues including cultural and language differences (Azizi, Gouva et al. 2003). Interventions that seek to provide culturally appropriate care for people of minority cultures fills a huge gap within current health systems worldwide (Brown 1998). Therefore the design and implementation of appropriate strategies for early diagnosis and treatment and population-based primary prevention of diabetes in these high risk populations is a public health and economic priority. Prospective approaches and prevention strategies for minority populations are often hindered by scarcity of data (Simmons 1999) therefore many interventions are not well known or in some circumstances not well received particularly from a research point of view.

## **Cultural components**

A number of components of successful interventions aimed at various cultures and high risk populations have been presented. All of which are crucial and have been implemented with full support from the communities involved. Other elements such as the use of elders, prayers and incantations, use of cultural myths, legends, story telling and differing religious activities may have been utilised in the design and implementation of the interventions although not explicitly reported in the studies reviewed. Reporting of the interventions aimed at Māori were similar and it was interesting to note that none of the studies revealed the use of karakia (incantations), kaumatua (elders), or koha (donation) all of which are intrinsically linked to Māori tikanga (ways) processes.

# Workforce issues

Culturally innovative interventions are often hindered by a lack of an appropriate and culturally competent workforce. As a result many interventions make successful use of 'community' based or 'lay workers' that is people from the targeted community who are trained to help with teaching, administering and implementing the intervention. Although most communities welcome this approach it is important to emphasize that which is consistently noted in literature in that this is not the ideal as there is a need to support and develop an appropriate cultural health workforce across all levels of the health sector (e.g. doctors, nurses, physiotherapists, podiatrists). Some communities preferred to have a health professional (a perceived authority figure) teaching the intervention and therefore workers from the community would support alternative aspects of the intervention equally vital to the programme (e.g. arranging and organising sessions, contacting and visiting patients, setting up equipment, transportation and assisting health professionals in the teaching of the programme) (Brown 1998; Azizi, Gouya et al. 2003).

# Conclusion

In conclusion diabetes has had significant and devastating impacts worldwide. Of particular concern are marginalised populations including ethnic, indigenous, and minority groups. The effects of diabetes not only impacts on individuals but also affects family members, communities and societies with the greatest impacts being physical, emotional and financial. These significant implications have caused governments worldwide to re-prioritize health strategies in order to prevent, reduce and monitor diabetes and diabetes-related complications.

A number of successful diabetes and diabetes related-foot interventions have been reported that have already been implemented both internationally and nationally. Interventions reported were both mainstream and cultural specific and were found to be most successful when tailored, targeted and implemented in consultation with, and for specific population groups. The review highlighted that there is no one universal intervention that will address all population groups. Findings highlight the need for interventions to be multifaceted and varied using multiple approaches that address specific issues for high risk populations. Interventions that are designed and developed in partnership with targeted communities and take into consideration, impacts of colonization, address the determinants of health, recognize diversity and uniqueness of various populations, as well as being adequately resourced will be most successful in preventing and reducing the impact of this deadly disease.

To ensure amputations prevention strategies aimed at Māori will be successful, New Zealand national and local strategies are needed that specifically focus on and recognize foot complications as an area of significant concern for Māori. Successful strategies for Māori are needed that incorporate both mainstream and cultural components, are developed in consultation with Māori communities and stakeholders, include messages that are simple, clear, consistent and appropriate, incorporate reciprocity, and respect, and support health priorities will be of most benefit in preventing, reducing and monitoring the impact of diabetes and associated complications whilst improving health outcomes for Māori.

Interventions that incorporate these components will not only benefit specific cultural and minority groups such as Māori but will also profit mainstream populations whilst reducing the burden of health system and health service costs.

Taupua Waiora

# APPENDIX TWO: INFORMATION AND CONSENT FORMS

## PARTICIPANT INFORMATION SHEET

#### Controlling diabetes related foot problems among Māori.

#### Invitation

You are invited to take part in this research project, which will involve being home visited by a Registered Nurse who will interview you about your health generally and your diabetes, take height and weight measurements and examine your feet. The Nurse will visit you a second time one year later to repeat the interview and measurements. If you are part of the group who do not receive podiatry care from your general practice provider then this is all we will be asking of you. If you are part of the group receiving podiatry care at your general practice provider, you will also be invited to take part in a weekend diabetes wānanga to give you practical advice and support for looking after your diabetes. You will also be given an appointment to visit the podiatry foot clinic at your GP service. The podiatry clinic will assess the health of your feet and provide you with any advice and treatment you might need. You will be encouraged to bring your whānau with you if you wish, to the diabetes wānanga and your foot clinic appointment. Your participation is entirely voluntary (your choice).

# What is the aim of this research?

The aim of the overall study is to develop and test a process for foot specialist services (podiatry services) which are accessible and acceptable for Māori. This has the potential to reduce diabetes-related foot problems among Māori.

#### How are people chosen to be asked to be part of this research?

Māori people aged eighteen years and over whom have diabetes and diabetes related foot problems and who have not been to the podiatry clinic in the last year will be invited to take part in the research.

# What happens in this research?

For all participants - You will be home visited by a Registered Nurse who will interview you, measure your height and weight, and examine your feet. This interview will take about 1 hour. The Nurse will visit you again one year later and repeat the same interview, measurements and foot examination. The questions you will be asked are about your general health, your diabetes, what you know and understand about diabetes and looking after your diabetes and how you feel about the health services you use. Because diabetes can affect your feet, the foot examination is to check the health of your feet. The purpose of repeating the interview after one year is to check whether or not there has been any change with your health, your diabetes and your feet. You do not have to answer all the questions and you can stop the interview at any time.

**Only for participants receiving podiatry care at the general practice provider** – You and your whānau, if you wish, will be invited to attend a diabetes wānanga. The purpose of the diabetes wānanga is to share information with you and give practical advice and support on how to manage your diabetes so that you stay well. You will also be invited to visit the foot specialist (podiatry) clinic at your GP service where you will have a foot assessment and be given any advice and treatment you might need. The assessment you receive will be a different assessment to people who are not part of the research project. The main differences are to do with checking your diabetes health generally, rather than just your feet. The podiatry clinic will give the research team information about what treatments you received for your foot problems and other services they may have recommended you use to prevent foot problems. In summary, we would visit you twice in your home, invite you to a wānanga and invite you to come to the podiatry clinic at your GP service. None of these appointments would cost you anything. At the end of the study you will continue to have access to the standard podiatry services at your GP clinic.



#### What are the benefits of the research?

Information gathered in this study will help us to understand how services need to be provided to help prevent foot problems among Māori with diabetes.

#### What are the discomforts and risks?

Talking about your health and wellbeing may be upsetting. We will give you a list of organisations and people to contact should you feel you want to talk further about any of the issues raised in the interview. Also if we find you have any urgent problems that need further assessment we will talk with you about this and whether we think you need to consult your GP. We will ask you for your permission to give your GP information about the urgent problem we think you need to see a GP about.

#### How will my privacy be protected?

Only the researchers will have access to the information we collect when we home visit you, unless we find you have an urgent health problem which we think you should talk with your GP about or attend an emergency department. We will ask you for your permission to pass on information to your GP if we find you have an urgent health problem. All the information from the interview will be coded so your name will not be used and the information will be locked in a secure cabinet at Taupua Waiora, the Centre for Māori Health Research at AUT University. This information will be destroyed after six years. None of the reports from the study will include any names. Your information that is collected at the podiatry clinic will be kept at the clinic as part of your health records for a period of ten years.

#### What opportunity do I have to consider this invitation?

You may call your primary health care provider or the research office to ask any questions you may have about this study. The research office contact details are at the bottom of this information sheet. You do not have to make a decision straight away. A researcher will call you in 1 week to ask you if you have decided to be a part of the study or not. If you agree over the phone to be part of the study, an appointment will be made for the Registered Nurse to visit you at your home. The Nurse will ask you to sign a consent form before beginning the interview. You can still change your mind at that stage. Your health care will not be affected in any way if you do not take part in this study. If you do agree to take part in the study you can withdraw from the study at any time, without having to give any reason.

#### What do I do if I have concerns about this research?

If you have any queries or concerns about your rights as a participant in this study, you may wish to contact a Health and Disability Advocate at the Health Advocates Trust, telephone **0800 555 050**.

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators.

#### Who do I contact for further information about this research?

Sonia Rapana Research Officer Māori Health Research Centre Auckland University of Technology Email: <u>sonia.rapana@aut.ac.nz</u> Phone: (09) 921 9999 ext 7395 Liane Penney Senior Research Fellow Māori Health Research Centre Auckland University of Technology Email: <u>liane.pennev@aut.ac.nz</u> Phone: (09) 921 9999 ext 7245

This study has received ethical approval from the Northern Y Regional Ethics Committee on 16 July 2007 Reference number NTY/07/06/061



#### MEMORANDUM

#### APPROVAL FORM: AUCKLAND UNIVERSITY OF TECHNOLOGY ETHICS COMMITTEE (AUTEC)

To:	Liane Penney
From:	Madeline Banda Executive Secretary, AUTEC
Date:	19 November 2007
Subject:	Ethics Application Number 07/198 A diabetes related lower limb pathology control demonstration intervention for Māori

#### Dear Liane

I am pleased to advise that the Auckland University of Technology Ethics Committee (AUTEC) approved your ethics application at their meeting on 12 November 2007. Your application is now approved for a period of three years until 12 November 2010.

I advise that as part of the ethics approval process, you are required to submit to AUTEC the following:

- A brief annual progress report indicating compliance with the ethical approval given using form EA2, which is available online through <u>http://www.aut.ac.nz/about/ethics</u>, including when necessary a request for extension of the approval one month prior to its expiry on 12 November 2010;
- A brief report on the status of the project using form EA3, which is available online through <u>http://www.aut.ac.nz/about/ethics</u>. This
  report is to be submitted either when the approval expires on 12 November 2010 or on completion of the project, whichever comes
  sooner;

It is also a condition of approval that AUTEC is notified of any adverse events or if the research does not commence and that AUTEC approval is sought for any alteration to the research, including any alteration of or addition to the participant documents involved.

You are reminded that, as applicant, you are responsible for ensuring that any research undertaken under this approval is carried out within the parameters approved for your application. Any change to the research outside the parameters of this approval must be submitted to AUTEC for approval before that change is implemented.

Please note that AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this.

To enable us to provide you with efficient service, we ask that you use the application number and study title in all written and verbal correspondence with us. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at <u>charles.grinter@aut.ac.nz</u> or by telephone on 921 9999 at extension 8860.

On behalf of the Committee and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely

Madeline Banda

Executive Secretary Auckland University of Technology Ethics Committee


## PARTICIPANT CONSENT FORM

## Project title: Controlling diabetes-related foot problems among Māori.

I have read and I understand the information sheet dated 31<sup>st</sup> May 2007 for volunteers taking part in the study designed to develop and test a process for foot specialist services (podiatry services) which are accessible and acceptable for Māori.

I understand that taking part in this study is entirely voluntary (my choice).

I have had this study explained and I have had time to consider whether to take part.

I have had an opportunity to use whānau support or a friend to help me ask questions and I am satisfied with the answers I have been given.

I know who to contact if I have any further questions about the study.

I understand that only my primary health care provider will be informed of my participation in the study.

I understand that the researchers will review my records held by my primary health care provider.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I understand that I may withdraw myself or any information that I have provided for this study at any time prior to, and up to 2 weeks following completion of data collection, without being disadvantaged in any way.

Written consent given to take part in the study tick one: Yes O No O I wish to receive a copy of the report from the research: tick one: Yes O No O

I \_\_\_\_\_\_ (full name) hereby consent to take part in this study.

Participant signature:

Date:

Sonia Rapana Research Officer Māori Health Research Centre Auckland University of Technology Email: <u>sonia.rapana@aut.ac.nz</u> Phone: (09) 921 9999 ext 7395 Liane Penney Senior Research Fellow Māori Health Research Centre Auckland University of Technology Email: <u>liane.penney@aut.ac.nz</u> Phone: (09) 921 9999 ext 7245

Approved by the Northern Y Regional Ethics Committee on 16 July 2007 Reference number NTY/07/06/061

Note: The Participant should retain a copy of this form.

# APPENDIX THREE: INTERVIEW SCHEDULES

## FOCUS GROUP INTERVIEW SCHEDULE

Health aspirations, knowledge, perceptions of diabetes, diabetes-related foot issues, barriers, and positive facilitating factors related to foot self management and control, podiatry-related service content and delivery preferences, indicators for measuring intervention effectiveness consistent with Māori community values and aspirations.

#### **Health Aspirations**

- If you were to develop your own service to help you to look after your diabetes what would it look like?
- Would the service look any different if you were to develop one for your family? If yes please describe?
- Knowledge
- Where / who have you gained most of your knowledge about diabetes from?
- Where are you currently most likely to go to access information to manage your diabetes from?
- What information would you want to know most about / least about please explain?

## **Perception diabetes**

- What are your greatest concerns about having diabetes?
- What are your greatest concerns about looking after your diabetes?
- Perception diabetes related foot issues
- What is your understanding of how diabetes affects feet?
- What advice would you give to some-one with diabetes about looking after their feet?
- What services are available to help you care specifically for your feet?

## Barriers

- What barriers hinder your ability to access services?
- What sort of a service are you least likely to access and why?
- Positive Facilitating factors
- What method of teaching most appeals to you? (Reading, doing, listening)
- What are the benefits of accessing information from this source?
- Who do you most trust to educate you about managing your diabetes? And why?
- What qualities would be needed in a person who would best help you to self manage your diabetes?
- What service do you most access and why?
- Is there any health programme which has had an impact on your health?
- What components did you find most useful?

## Service Content

- What setting would most appeal to you when learning how to mange your diabetes?
- In terms of time how much are you able to commit to education about managing diabetes?
- What is your preference in terms of being taught, individually or within a group?
- What topics do you think should be covered when learning about diabetes?
- -Who do you think would be best to teach about diabetes?
- When learning what median have you learnt a lot from?
- Service Delivery Preference
- What would be included in a service for you and or your family to access services to help you to manage your diabetes?

## Other

• Are there any other issues you would like to raise, or comments you would like to add?

# INTERVIEW SCHEDULE FOR KEY INFORMANT INTERVIEWS

- What are the main barriers to health care for diabetes-related foot problems for Māori?
- What do you think are the key factors that facilitate health care for diabetes related foot problem for Māori?
- What do you think are the main barriers for Māori with diabetes in self management of their feet?
- What do you think are the key factors that facilitate good foot self care and management for Māori with diabetes?
- What would be the ideal diabetes related podiatry education programme for Māori, in terms of content and delivery style?
- If you were to devise an ideal podiatry service to meet the health needs and aspirations of Māori with diabetes, what would the essential components and characteristics of that service be?
- How could a podiatry service be seamlessly integrated into existing health and social services?
- Are there any other issues you would like to raise, or comments you would like to add?

# APPENDIX FOUR: SUMMARY OF BASELINE AND 12 MONTH FOLLOW-UP SURVEY AND PODIATRY FOOT ASSESSMENT

## INSERT SURVEY AND PODIATRY FOOT ASSESSMENT

The final survey consisted of 70 questions in total about the following issues. (Because of the survey size, a summary only of the types of questions contained in the survey are provided here. The original survey can be provided on request at Taupua Waiora AUT 921 9999)

Health care that the person had received recently (9 questions)

Eg: How often do you check your feet for signs of problems?

Diabetes related questions (7 qns)

Eg In the past year, has your health care provider made changes in your insulin or pill dose on the basis of your home blood tests?

Diabetes related care provision (2 qns)

Eg I'm very satisfied with the diabetes care I receive (rating Strongly Agree-Strongly Disagree)

Knowledge about diabetes and how to take care of diabetes (10 qns).

Eg Why are foot checks important in someone with diabetes? Why is it important to look at your feet? What are you looking for?

How the person feels they understand diabetes and diabetes care. (1 qn a-k)

How do you rate your understanding of: the role of exercise in diabetes care (Rating Poor/Good/Excellent)

Other health problems the person may have (12 Qns)

Eg Have you ever had an amputation of a toe, foot, partof a leg, or all of a leg for a poorly healing sore or poor circulation? (An amputation that is not due to an injury or accident [car crash, power tool injury, war injury, etc.])?

The next section implemented the SF12, which is a rating scale of views about one's health, how a person feels and how well they are able to do their usual activities (Physical and Emotional health)

Eg During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?

During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.) (rating)

The next set of questions asked about physical activity, smoking and drinking alcohol (17 Qns).

Eg During the last 7 days, on how many days did you walk at a brisk pace - a brisk pace is a pace at which you are breathing harder than normal? This includes walking at work or school, while traveling from place to place, at home, and at any activities that you did solely for recreation, sport, exercise or leisure.

How often during the last year have you found that you were not able to stop drinking once you had started?

The final general questions were about ethnicity, qualifications, employment, income and contact details (15 qns)

Eg In the last 7 days, did you have one job or more than one job in paid employment? (Count any job for pay profit or income, and any job in a family business or family farm, without pay.)

Longitudinal Podiatric Foot Assessment. The final 15 questions focused on foot health care.

Eg Do you get a pain in either leg on walking.

As part of questions 6, a further group of questions were developed and implemented for administration to the intervention group at the second interview. The questions were about the application, use and impact of the intervention for participants. These questions were:

Q6 b Were you issued the emollient foot cream? Yes/No/Do not remember

Q6 c How often in the last year did you use the emollient foot cream? Not at all/Monthly/Daily/Weekly

Q6 d Did the podiatrist give you the special diabetes (merino wool) Socks? Yes/No/Do not remember

Q6 e How often in the last year did you use the special diabetes (merino wool) Socks? Not at all/Monthly/Weekly/Daily

Q6 f What difference have the socks and emollient cream given to you by the podiatrist made to you and your whānau?

Q6 g How have you and your whanau felt about involvement in this study?

Q6 h Have the other professionals that the Podiatrist referred you to made a difference to your foot care? If yes, how and why?

Q6 i What difference has the information given to you by the Podiatrist at each clinical appointment made to your foot care?

Q6 j What difference has the information given to you at the Education Wānanga made to you and your whānau?

The questionnaire was administered twice - once at the start and once at the end - of a twelve month period to both the control and intervention group participants. Question 6 was only included in the second administration to the intervention group

## APPENDIX FIVE: QUESTION 6

Follow up questions
Q6 b Were you issued the emollient foot cream?
1 No
2 Yes
□ 3 Do not remember
Q6 c How often in the last year did you use the emollient foot cream?
□ 1 Not at all
2 Monthly
□ <sub>3</sub> Weekly
4 Daily
Q6 d Did the podiatrist give you the special diabetes (merino wool) Socks?
1 No
$\square_2$ Yes
□ 3 Do not remember
Q6 e How often in the last year did you use the special diabetes (merino wool) Socks?
□ 1 Not at all
2 Monthly
3 Weekly
4 Daily
Q6 f What difference have the socks and emollient cream given to you by the podiatrist made to you and your whānau?

Q6 g How have you and your whānau felt about involvement in this study?

Q6 h Have the other professionals that the Podiatrist referred you to made a difference to your foot care? If yes, how and why?

Q6 i What difference has the information given to you by the Podiatrist at each clinical appointment made to your foot care?

Q6 j What difference has the information given to you at the Education Wānanga made to you and your whānau?

## APPENDIX SIX: JUSTIFICATION AND OPERATIONAL DEFINITION OF PODIATRIC INTERVENTION5

#### Podiatric Assessment

Wu et al [2006] in a review of current evidence reported that lower extremity complications in persons with diabetes have become an increasingly significant public health concern in both the developed and developing world. These complications, beginning with neuropathy and subsequent diabetic foot wounds frequently lead to infection and lower extremity amputation even in the absence of critical limb ischemia. In order to diminish the detrimental consequences associated with diabetic foot ulcers, a common-sense-based treatment approach must be implemented. Many of the etiological factors contributing to the formation of diabetic foot ulceration may be identified using simple, inexpensive equipment in a clinical setting. Prevention of diabetic foot ulcers can be accomplished in a primary care setting with a brief history and screening for loss of protective sensation via the Semmes-Weinstein monofilament. Specialist clinics may quantify neuropathy, plantar foot pressure, and assess vascular status with Doppler ultrasound and ankle-brachial blood pressure indices. These measurements, in conjunction with other findings from the history and physical examination, may enable clinicians to stratify patients based on risk and help determine the type of intervention. Other effective clinical interventions may include patient education, optimizing glycaemia control, smoking cessation, and diligent foot care. However, it is imperative to remember the fundamental basics in the healing of diabetic foot ulcers: adequate perfusion, debridement, infection control, and pressure mitigation. Early recognition of the etiological factors along with prompt management of diabetic foot ulcers is essential for successful outcome.

Singh et al (2006) undertook a systematic review on the efficacy of methods advocated for preventing diabetic foot ulcers in the primary care setting. They reviewed the retrieved literature for pertinent information, paying particular attention to prospective cohort studies and randomised clinical trials. The authors reported that the prevention of diabetic foot ulcers begins with screening for loss of protective sensation, which is best accomplished in the primary care setting with a brief history and the Semmes-Weinstein monofilament. Specialist clinics may quantify neuropathy with biothesiometry, measure plantar foot pressure, and assess lower extremity vascular status with Doppler ultrasound and ankle-brachial blood pressure indices. These measurements, in conjunction with other findings from the history and physical examination, enable clinicians to stratify patients based on risk and to determine the type of intervention. Educating patients about proper foot care and periodic foot examinations are effective interventions to prevent ulceration. Other possibly effective clinical interventions include optimizing glycaemia control, smoking cessation, intensive podiatric care, debridement of calluses, and certain types of prophylactic foot surgery. The value of various types of prescription footwear for ulcer prevention is not clear. The authors concluded that substantial evidence supports screening all patients with diabetes to identify those at risk for foot ulceration. These patients might benefit from certain prophylactic interventions, including patient education, prescription footwear, intensive podiatric care, and evaluation for surgical interventions.

<sup>&</sup>lt;sup>5</sup> Justification & Operational Definition of Podiatric Intervention (Prof K Rome 17/9/2007)

#### **Podiatric Interventions**

Uda et al [2005] reported that rough skin or xerosis, known by the laity as dry skin, results from a defect in the stratum corneum desquamation which normally remains imperceptible. This condition is negatively influenced by winter climatic conditions. Atopic dermatitis and trophic changes related to post-menopause, ageing, diabetes mellitus, as well as other endrocrine and metabolic disturbances are also involved in this process. Xerosis can be improved at various degrees by emollients, humectants, hydrating agents and squamolytic agents.

Phem et al [2002] undertook a prospective, randomised, controlled double-blind study was conducted to compare the efficacy of a test moisturizer containing 10% urea and 4% lactic acid versus its emulsion base vehicle in the treatment of xerosis of the feet in patients with diabetes. Forty patients (mean age 62 +/- 11 years) with diabetes and moderate-to-severe xerosis of both feet were enrolled. Xerosis severity was assessed using a nine-poInterview Xerosis Assessment Scale. The tested moisturizer was applied to one foot and the vehicle to the other, twice a day, for 4 weeks. The regression of xerosis also was evaluated 2 weeks following discontinuation of the treatments. Progress was noted weekly with photographs and examination. Feet treated with the vehicle cream (control) had an initial mean xerosis grading of 6.17 (+/- 0.79) and a final xerosis grading of 4.38 (+/-2.20). In the treatment group, mean xerosis grading diminished from 6.13 (+/- 0.73) to 3.19 (+/- 2.23) after 4 weeks (P < 0.01). The difference between control and treatment remained statistically significant following discontinuation of cream application. In this study, regular use of a moisturizer was found to be beneficial in the treatment of moderate-to-severe xerosis of the feet in patients with diabetes. The cream containing 10% urea and 4% lactic acid provided faster and better improvement with significantly less xerosis regression. Jennings et al [2003] also reported that used twice daily for 4 weeks, pure lanolin and ammonium lactate cream were both effective in treating moderate to severe xerosis.

Garrow et al (2005) examined the ability of preventive foot care (PFC) socks to reduce plantar foot pressures in a sample of high-risk patients with diabetes. The results from the study suggest that the wearing of PFC socks increases the underfoot contact area and hence decreases plantar foot pressures. Murray et al [1990]: assessed the acceptability of specially designed socks to provide satisfactory pressure relief in the insensitive, high-risk, diabetic foot. The results found that the experimental socks had a high level of patient satisfaction when worn with suitable shoes, and may be an acceptable and inexpensive addition to existing methods of protecting the high-risk insensitive diabetic foot.

## **Podiatric Intervention Programme**

Calle-Pascual et al (2002): conducted a study in Spain to assess the efficacy of a preventative foot care programme, applied in a normal outpatient setting to decrease the incidence of foot ulcers in people with diabetes diagnosed as having neuropathy by neuropathy disability score (NDS), in relation to the severity of neuropathy based on the vibration perception threshold (VPT). A structured continuous preventative foot care programme was designed to ensure proper footwear, walking foot hygiene, callus care, nail cutting, water temperature checks, use of warming devices, bathroom surgery, foot care products and self-inspection. Continual foot-care education and treatment, including podiatry, were available. Evaluation was at least every 6 months. Diabetic patients (n=308) with neuropathy (NDS > or =6), 72.3+/-10.7 years old, 45% men, 10.9+/-8.8 years duration of diabetes,

and HbA(1c) 6.5+/-1.3%, without a history of foot lesions were recruited over 3 years and followed-up for 4.6 (3-6) years. A low risk group (n=124) had a VPT<25 V while 184 had a VPT > or =25 V (high risk). In all 220 patients (71%) complied with the programme, compliance being 76 and 68% in low and high risk groups. The low risk group developed nine ulcers in nine patients, and the high risk group 24 ulcers in 19 patients. Of these eight and 19 ulcers, respectively, were in the non-compliant patient group, giving relative risk of 22 and eight compared with people attending the programme. Thus compliance with a preventative foot programme reduces the incidence of foot ulceration in people with diabetes with neuropathy. This decrease is relatively greater in patients with less severity of neuropathy.

Rönnemaa et al (1997) evaluated the influence of podiatrist activities on the outpatient care of diabetic patients in terms of knowledge of diabetic foot care, self-care, and minor foot problems in Finland. 733 patients, aged 10-79 years, identified from the national diabetes register. Patients without recent visits to a podiatrist and without an obvious need for foot care were randomised into a podiatric care group (education and primary prevention measures, n = 267) and a control group (written instructions only, n = 263). The patients were examined by an independent study podiatrist at baseline and after 1 year. The results demonstrated patients in the podiatrist group had greater improvement in knowledge of diabetic foot care (P = 0.004) and self-care (P < 0.001) scores compared with control subjects. The prevalence of callosities in regions other than the calcaneal region decreased more (P = 0.009) in the podiatrist group (from 54.5 to 39.5%) than in the control group (from 51.3 to 48.2%), and the size of the callosities decreased more (P < 0.001) in the podiatrist group than in the control group. Reduction in the prevalence of callosities was associated with younger age (< 50 years). In conclusion the authors reported that education and primary preventive measures provided individually by a podiatrist result in significant improvements in knowledge and foot self-care scores and in improvements in the prevalence of some minor foot problems.

Plank et al (2003) evaluated the influence of regular podiatrist care in Austria on the recurrence rate of diabetic foot ulcers within 1 year. Ninety-one diabetic outpatients with healed foot ulcers were randomised to a group that received monthly remunerated routine podiatrist care (n = 47) or a control group (n = 44). The results demonstrated a median follow-up of 386 days; ulceration recurred in 18 patients in the podiatrist group and 25 patients in the control group. Analysis of ulceration per foot demonstrated a significant reduction in favour of podiatrist care. Per protocol, analysis of patients who actually underwent podiatrist foot care on a regular basis also indicates the beneficial influence of podiatrist care with ulceration in 13 vs. 30 patients and in 15 vs. 37 feet for the intervention and control groups, respectively. Minor amputation was required in two patients in the intervention group and one patient in the control group. Four patients in the control group and two patients in the intervention group died during the trial. The authors concluded that secondary preventive measures by a podiatrist may reduce recurrence of foot ulcers in diabetic patients.

#### **Operational Definition**

Based on previous evidence and current thinking the operational definition of the podiatric intervention will be "participants that have been assessed by a podiatrists using the diabetes foot screening and assessment tool will be classified into category groups 2-6 will then receive the specific podiatric intervention." Any participant identified under category 1 will not receive the podiatric intervention.

The podiatric intervention will consist of the following:

- Self-use of emollients;
- Prescription of specialised socks specifically designed for diabetics;
- Prescription of foot orthoses for participants based on podiatric biomechanical examination and assessment ;
- Self-management education session that includes foot hygiene, daily inspection of feet and the use of appropriate footwear;
- Referral to specialists within the diabetic field;
- Referrals to other primary care services.

\* Based on participants needs

Verbal instructions will be given to all participants on the use of socks, emollients and foot orthoses. This will be reinforced at the education away day.

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## APPENDIX SEVEN LIFESOCK



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