

# STROKE: A PICTURE OF HEALTH DISPARITIES IN NEW ZEALAND

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## Abstract

The experience of Māori stroke survivors and their caregivers is the focus of this paper. A series of qualitative face-to-face interviews was conducted, firstly with Māori who had experienced stroke, and who were part of the 2002/03 Auckland Regional Community Stroke (ARCOS) study; and secondly with their primary caregivers. Experiences of Māori stroke survivors and caregivers are presented under the following themes: experience and knowledge of stroke, experience in hospital and the importance of cultural identity in motivating rehabilitation, the financial impact of stroke on Māori whānau, the stigma and social isolation associated with stroke and health services, and the associated policy issues that emerge from these interviews for Māori.

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## INTRODUCTION

Stroke is a preventable disease, yet it is the third leading cause of death in New Zealand after cancer and heart disease, and it is the greatest cause of disability in older people (Tobias et al. 2002). Over 7,000 New Zealanders each year will experience a stroke event, and of this population at least three-quarters will die or be dependent on others for care one year after the event (Gommans et al. 2003). Although so many people each year will experience a stroke event, access to, co-ordination and quality of stroke services vary across the country (Wilkinson and Sainsbury 2003). The purpose of this research was to provide ethnic-specific qualitative information to complement the quantitative results from the 2002/03 Auckland Regional Community Stroke (ARCOS) study (Anderson et al. 2005, Carter et al. 2006). This paper only reports interviews with Māori stroke survivors and their primary caregivers; other ethnic-specific interviews have not yet been published.

The World Health Organisation defines stroke as a sudden-onset, focal or global neurological deficit lasting more than 24 hours or leading to death, and excludes transient ischaemic attacks (Tobias et al. 2002). For those Māori who experience stroke, the impact on them, those who provide care and their wider whānau is substantial.

Disparities in health become clearly visible when comparing both coronary health and cardiovascular outcomes between Māori and Pākehā (European New Zealanders). At present, coronary heart disease is the leading cause of death for both Māori males and females, and the coronary heart disease mortality rate for Māori under 65 years of age is almost three times higher than for non-Māori in the same age group (Ministry of Health 2003).

The average age of stroke onset for Māori is 61 years, compared to 64 years for Pacific people and over 75 years for European New Zealanders (Feigin et al. 2006). There is also some evidence that the chance of being dependent at 12 months post-stroke is three times higher for Māori compared to Pākehā (McNaughton et al. 2002, Ministry of Health 2003). There are also gender differences in relation to stroke, such that women on average experience stroke at a later age than men (at approximately 76 years), and Māori and Pacific women experience stroke on average 15 years earlier than European women in New Zealand (Dyall et al. 2006).

National guidelines for the management of stroke recognise the different onset of stroke for Māori compared to non-Māori (Moewaka-Barnes and Tunks 2002, Stroke Foundation New Zealand 2003). To address Māori needs, it is recommended that providers of stroke services work with local Māori providers, address barriers to stroke care and involve whānau in the development of care for Māori stroke survivors.

There is no mention in the national guidelines of recognition of Te Tiriti o Waitangi (Treaty of Waitangi). This is despite the Ministry of Health's recognition that it is appropriate for the health sector to address health inequalities for Māori from a Te Tiriti o Waitangi context, taking account of the historical circumstances that have occurred for Māori, such as loss of land, loss of economic and social assets, and the impact of colonisation which continues to affect the health and disability status of Māori today (Ministry of Health 2002).

A health inequalities framework has been developed by the Ministry of Health to help explain and address health inequalities for Māori and ethnically disadvantaged populations. The framework recognises how health inequalities are created within society and outlines steps that can be taken to address structural arrangements in society which create inequities, such as the importance of improving income, employment, education and health status for disadvantaged ethnic populations. In addition, it is important to support Māori and other disadvantaged populations to have greater control over the environments they live in, as well as providing support to assist individuals and populations to develop healthy lifestyles. It is also advocated that health and disability services be appropriately resourced in relation to need. Support should be given to those who are disadvantaged by health or disability, for example, by providing appropriate income support and addressing ethnic, racial and social discrimination, and assistance should be provided for those who provide informal or formal care for the disabled (Ministry of Health 2002).

It is important to understand the context of why Māori have a different experience of stroke from other populations in New Zealand (Stroke Foundation New Zealand 2003). This paper identifies issues that are important for Māori and raises policy issues related to stroke and Māori access to health and other support services. The paper raises the need for further research and inquiry into how health and disability disparities for Māori can be addressed to improve their experience and health outcomes from stroke.

## SUBJECTS AND METHODOLOGY

A qualitative study was undertaken interviewing *kanohi ki te kanohi* (face-to-face) Māori stroke survivors and their primary caregivers. Fifteen people who self-identified as Māori were interviewed: eight were Māori stroke survivors, of whom four were females under 60 years old and four were males aged over 60 years. Seven Māori caregivers were interviewed, of whom six were females. They were connected to the stroke survivor through one of the following relationships: wife, sister, daughter or granddaughter, and the male interviewed was the husband of a stroke survivor.

A semi-structured questionnaire was developed to guide the interviews. The number of participants interviewed was related to the resources of the study. Possible participants were identified through the Stroke Foundation during the ARCOS 2002/2003 study. They were contacted by letter informing them about the study, and then contacted by phone to inquire whether they were interested in participating. If so, a time was arranged to meet. All participants were again informed about the study, and informed consent was obtained.

Participants were interviewed by two Māori researchers (Anderson et al 2005). Prior to the start of the interviews participants' ethnic identity was asked again to confirm whether they identified as Māori. Appropriate Māori protocol was accorded to all participants, with each interview recognising spiritual, ancestral and tribal connections. Two researchers were present at each interview with the stroke survivor, so that one researcher could interview the stroke survivor and the other could interview the caregiver separately. This arrangement enabled both participants to freely discuss their experience of stroke.

All interviews were taped and transcribed. They were then read by the Māori interviewers and other members of the research team who were responsible for interviewing other stroke survivors and caregivers from different ethnic groups (Carter et al. 2006). All transcripts were then coded to a schedule developed by the research team to analyse the information provided.

A range of stroke survivors was sought through the research process to enable diverse experiences of stroke to be recorded which reflected participants' differences in age, gender, family situation and health lifestyles. This study was funded by the Health Research Council of New Zealand and received ethics approval from the Auckland Ethics Committee.

## RESULTS

The results are presented in relation to the themes that emerged from the interviews.

### Stroke is a Frightening Event

All Māori stroke survivors and their primary caregiver found stroke a frightening event, as it was unplanned and outside of their control, and they had to call on hospital services for help. The length of time spent seeking help depended on their understanding of the event, whether family assistance was available to arrange or provide transport, and consideration of whether those involved believed alternative care might be more effective.

All Māori stroke survivors had different experiences in relation to their stroke, but commonly describing it as a devastating experience, because it was an event you could not stop, it made you physically ill, and you were left with ongoing consequences.

"It's just something that came over me which I couldn't control. I didn't know at the time it was a stroke. At the time I couldn't explain anything. I was useless. I was up in the world visiting Mars and the old ancestors ... Stroke has been devastating ... I don't think I would like it to happen to anyone, even to my worst enemy." (Male stroke survivor)

"I knew there was something wrong, because I had been to the hospital several times for congestive failure. I thought this was it." (Male stroke survivor)

"I lost feeling in my right arm and I couldn't think." (Female stroke survivor)

"First stroke – easy recovery. The second stroke took me out, flat out." (Female stroke survivor)

Caregivers also found the event frightening, but as an observer they had greater awareness of what was happening or what had occurred. Generally their immediate reaction was to seek medical help by calling an ambulance or taking the person to their nearest hospital.

One caregiver who lived some distance away from her father had a feeling that her father was unwell. On arrival at his place she found him on the floor and noticed "the drooping of the mouth and the confusion". From there she had to make a decision between alternative health care or hospital care. She tried alternative health care for a month, and then when her father had not improved she sought medical care. The use of alternative or traditional health care was not unusual for Māori, sometimes sought before medical assistance or used concurrently.

#### Health Services: A Challenging Experience for Māori Stroke Survivors and Caregivers

Caregivers and whānau members participating in the study reported being keen to be involved in their kin's care and treatment decisions, and provide information about the patient's previous health conditions, their medication and dietary needs. Some said the information they provided was sometimes ignored by hospital staff, who were focused on the patient's stroke and not their other health conditions or the requests made by the family.

One caregiver said she had requested specifically that the hospital staff consult her on any major decision regarding the health care of her husband, because he had diabetes, but arrived at the hospital to find her husband about to be given shock treatment. She

"The head surgeon yelled at me and said 'No one told me that he was diabetic'. Well, I said, you should have gone and checked. He was screaming at me, so I screamed back at him." (Female caregiver)

One caregiver made a point of carrying with her at all times information regarding her father as he moved from one health facility to another in order to keep staff abreast of his details. She was critical of both Māori and mainstream services as promising to help but not delivering to her expectations. However, she found the Stroke Foundation informative and helpful to her in supporting her father.

"It's sad to see our old people sitting in these homes, you know, being promised that they've got these activities. You go in there and they're still in their bed, and they're still in their room." (Female caregiver)

This caregiver also identified income-testing and asset-testing for access to residential care as an issue for Māori, as she was afraid that it opened up the possibility of the loss of Māori land secured through whakapapa (genealogy). She explained that her father had already cost her family substantially when living with them, and now she visited him at least twice a day at his rest home to ensure he was comfortable. At the same time she and her husband also looked after their eight children, who were all at home and a number were still preschoolers. Her involvement in the everyday care of her father restricted her participation in school and community activities with her children and her time available for her family.

### Mental Health Assessment

The same caregiver considered that questions assessing mental competence directed to her father, a Māori elder, were inappropriate.

"The Pākehā said, 'We have to get a psychiatrist to assess him'. I said, 'What, he's not crazy'. They don't accommodate our Māori people, because if they can't speak English clearly and precisely. I mean, I walked in on an assessment and they asked him, 'What day is it? What is the time? What season?' I said, 'If it's raining outside, you put a raincoat on'. You know, what stupid questions to ask a person who has had a stroke." (Female caregiver)

Generally, Māori caregivers believed that hospital and community services for Māori stroke survivors could be improved. This could be achieved by considering caregivers' requests to be involved in their kin's treatment, using the information caregivers provided, developing appropriate cultural assessments and assuring caregivers that residential care policies protected Māori assets, both individually and collectively.

### Māori Identity: An Important Attribute

Identifying as Māori was considered important both by stroke survivors and their caregivers as giving them the strength and resilience to tackle the challenges they faced. Some described this in terms of being a “stubborn Māori” and said this attitude assisted them to overcome the barriers they faced in rehabilitation, accessing appropriate health services and coping with the financial difficulties associated with having stroke.

One survivor said being stubborn and identifying as Māori provided the motivation to challenge the prognosis of being in a wheelchair for the rest of his life.

“Two days later I started to drag my way along. I tried to motivate myself to be able to lift myself without any assistance, after being told I’d be spending the rest of my life in a wheelchair. I suppose some Māori are stubborn.” (Male stroke survivor)

Taking control of the situation, having faith in oneself, massage and exercise were typical responses of Māori stroke survivors to try to regain what they had lost and achieve as much independence as possible.

Caregivers supported such efforts. They also made conscious changes to improve the health of the stroke survivor by buying food that was healthy and less fatty, encouraging exercise, and supporting each other to give up smoking.

### Financial and Social Impact of Stroke: A Ripple Effect

Because Māori tend to be younger than Pākehā when they have a stroke, they are less likely to be eligible for New Zealand Superannuation and more likely to have families dependent on their income. Participants said their loss of income from employment substantially affected their self-esteem and the wellbeing of their whānau, often requiring another person to give up their employment to become the lead caregiver. Thus stroke created significant financial problems for these Māori whānau.

One man explained that prior to his stroke he had been a cultural advisor. In this position he had been held in high esteem by his colleagues and clients, who were young Māori attending an alcohol and drug rehabilitation programme. After the stroke he could no longer hold his job and was now reliant on government income support. Major changes had taken place within his whānau. His wife explained that to care for her husband, her daughter had stopped working, but he preferred for his wife to look after him. As a consequence of her husband’s stroke and family members’ inability to cope with the resulting stress, the family now relied on her for financial and emotional support. In particular she feared her mokopuna (grandchild) might attempt suicide,

as his grandfather was his significant male role model, and now they were unable to engage in the activities that they used to do together.

*"My eldest grandchild ... he is the one I have got to watch, because, I mean he's savage now, because he hates the fact that his grandfather is unable to take him where they normally used to go." (Female caregiver)*

### Improved Relationships

Ironically, having a stroke sometimes changed a person's personality for the better, and this enabled the stroke survivor and the caregiver to cope positively with the situation and for relationships to be re-established or maintained. One stroke survivor explained that his stroke provided a new opportunity to establish a relationship with his sister and wider whānau.

*"I don't see them much. I see my sister, but I think I could face them now. I couldn't face them before. I was angry. I was an angry man. I don't know why, but the stroke sort of changed me and turned me right around. Then I could sit down and speak to them ... The difference I have found is that I don't seem to worry about going back to work. I used to worry like hell before. It used to agitate me when they said don't go back to work, but it doesn't really matter much now." (Male stroke survivor).*

Sometimes relationships did not work out so well. One caregiver said that she often worried about her brother, and was torn between meeting his needs and the demands of her husband.

*"I try and share my life, you know, with both of them, and yet when we are alone [my husband] doesn't seem to talk. But when my brother's around he wants to talk, to get all of my attention, you see." (Female caregiver)*

Another stroke survivor explained that without her family and their involvement in her care she would not have recovered as well as she has. Her family responded to her stroke in a similar manner to organising a significant event on a marae. Everyone in the whānau was assigned a specific role and responsibility to perform, so that all could contribute to her wellbeing.

*"You underestimate your immediate family. They are so supportive of every achievement. If it wasn't for the support of my family I would not have achieved so much. They were the extra team you already had ... My son, who had to compete with his sister, he was there as a crisis manager. He was the contact person and delegated to each family member a task. All felt important about that. To me it was really lovely, and he is still doing it." (Female stroke survivor)*



This survivor believed that whānau members should collaborate with health professionals in developing the most appropriate rehabilitation programme for the person concerned, so that they could all be involved and could understand the nature of stroke and cardiovascular disease. As someone who had been heavily involved in supporting her local marae, she thought that rehabilitation programmes for stroke survivors should be provided on the marae, and that this would only require gym facilities with appropriate equipment and space for a therapist.

“Love to see a rehabilitation-type facility at the marae. Only need room for a gym, a room for therapist. Why should our Māori people have to go to the rehab unit? Why couldn’t you take it to the marae and get back into the community?” (Female stroke survivor)

This survivor also considered that the roles and responsibilities of whānau members should be defined in relation to emotional and social support. From her perspective, she considered it was important that people from outside of the family be able to be contracted to provide specific help, such as home help. As a grandmother, she felt humiliated at having to ask her mokopuna to do very personal tasks for her, and felt more comfortable negotiating tasks with paid help.

### Stigma and Stroke

Lack of social contact, isolation and feeling whakamā (embarrassed) were common experiences felt by Māori stroke survivors. For Māori, the most tapu or sacred part of the body is the head, and stroke can create both physical and cognitive changes for the person concerned. The stigma of having had a stroke made some Māori stroke survivors withdraw from participating in many Māori and wider community activities. Their social world was reduced, and their only connection to the outside world was through their family.

One stroke survivor explained that previously she had been totally involved in her community and marae for over 45 years. Since her stroke she no longer felt comfortable going to her marae, attending local church services, attending important tangihanga (funerals) or allowing local people to visit her. She explained that, for her, stroke was similar to a mental illness, because your behaviour and emotions were unpredictable. Her world was now focused on her family, and in particular her husband, because she no longer had confidence to be on her own.

“My uncle died last week. He was a good buddy, and I couldn’t get up there to the marae. I will just remember him as I remember him. I miss him and familiar people. I have been involved in my marae for over 45 years, but now I only want to see my own immediate family.” (Female stroke survivor)

## Information and Care

All Māori stroke survivors and caregivers expressed concern at the limited information that was provided to assist them to understand the process of recovery from stroke. Lack of information made it difficult for them to identify how well they were doing in relation to recovery and achieving defined milestones of success. Information received from the Stroke Foundation was appreciated.

There was, however, considerable criticism of the lack of caring and information received from health professionals, both in hospital and in the community. Services from speech therapists and physiotherapists were appreciated, especially those who made home visits.

## Health Services: Room for Improvement

Māori stroke survivors who were under the care of hospital diabetes services were more knowledgeable about stroke as a health event and the process required for effective rehabilitation than those who were being cared for by stroke and other services. Most Māori stroke survivors and caregivers were dependent on support from the survivor's or caregiver's general practitioner. The support received from general practitioners varied very widely. Those health practitioners who took the time to explain what had happened and the likely outcome were appreciated.

"It felt really neat that the doctor actually came here to sit down and korero [talk] to me about my Mum and what is happening to her ... It took a lot of worry off my mind. She never beat around the bush – she got straight to the point and told me what the current situation was." (Female caregiver)

## DISCUSSION

Interviews with Māori stroke survivors and their primary caregivers illuminate the factors that influence health inequalities, such as limited income, loss of employment, poor communication and relationships with health professionals, reduced health status, discrimination and stigma. For all of the participants, survivors and caregivers alike, the experience of dealing with stroke was a significant event in their lives, with flow-on consequences. On average, Māori die six to eight years earlier than non-Māori, and Māori experience stroke on average 14 years earlier than non-Māori.

## Communication

Interviews show the value that participants placed on good communications with health professionals, and how much they wanted to share their information with

professionals to ensure that their family members had positive outcomes from utilising health services. Although the importance of communication between stroke health care workers and Māori is emphasised in the national stroke guidelines (Stroke Foundation New Zealand 2003), the interviewees indicated that they believed this was an area where improvements could be made.

If health care workers make treatment decisions without receiving or considering the information offered by whānau members, it is possible that these decisions could place stroke survivors' health at risk or destabilise other health conditions. There may be some value to be gained from ensuring that the best possible use is made of this information and from inviting whānau members to participate in treatment and rehabilitation planning for stroke survivors.

### Māori Diabetes and Stroke

Interviewees who had diabetes and were already linked up with hospital services seemed to have been able to access other health care services. They were informed about the cause and effects of stroke and the stroke rehabilitation process. Diabetes mellitus has been identified as one of the major risk factors that increases the prevalence of stroke, and is most commonly associated with stroke in Māori patients compared to other ethnic groups in New Zealand (Carter et al. 2006). Diabetes mellitus has also been implicated as one of the possible causes of ethnic disparities in stroke incidence in our country (Anderson et al. 2005).

Māori should be consulted in future planning and development of stroke services in New Zealand. Consideration should perhaps be given to linking diabetes and stroke services, rather than seeing stroke as a separate service.

### Health Disparities and Social Isolation

When Māori experience a stroke event they are likely to be in their middle adult years, to be working, and to have other health problems such as diabetes or coronary disease. For all participants in this study, both survivors and caregivers, stroke was a devastating experience. It completely changed their lives and how their whānau functioned.

For the majority of Māori stroke survivors interviewed, the experience of stroke involved many losses, such as loss of financial independence, loss of mana (prestige) and loss of participation in community and cultural activities. On the other hand, the losses were sometimes compensated for by increased family contact, changes in personality that allowed them to cope better with their situation, and positive changes in their lifestyles to improve their health.

For the caregivers interviewed, their life and daily activities were almost entirely determined by the needs of the stroke survivor and wider family obligations. Like stroke survivors, they also experienced losses, such as loss of income, employment and friends. The experience of stroke within a Māori whānau was seen to have many ripple effects, and may contribute to increased social, economic and health disparities, and also to social exclusion. The stigma of having a stroke was felt by stroke survivors and their caregivers. Any stroke rehabilitation programme must also focus on the needs of whānau members. There is also a need for the general public to be informed about the cause and effects of stroke so that a supportive, non-discriminatory environment exists for stroke survivors and their caregivers in the community.

The number of Māori people in the community who experience stroke in New Zealand is predicted to increase as the population ages, and the effects of diabetes become more visible. This is in contrast to the finding that the overall incidence of stroke has fallen in New Zealand, as captured by the ARCOS studies (Carter et al. 2006). Overall, it is predicted that the number of people who will experience and survive a stroke will increase with an ageing population, and this has implications for the future planning and funding of health, disability and support services (Tobias et al. 2002).

### Māori-Specific Services

Identifying as Māori was defined by participants as a positive attribute that assists Māori stroke survivors to cope with their situation and to develop their own rehabilitation strategies. The Māori stroke survivors interviewed said that future stroke services should be supportive of Māori values, recognise the place of Māori in New Zealand, involve Māori whānau in stroke rehabilitation plans, and be located on marae or in settings that were accessible to and comfortable for Māori.

Policies that support Māori in rehabilitation or rest home care were also identified as an area that requires clarification and possible review. Interviewees were worried that current income and asset testing requirements to access rest home care might require some Māori individuals over 65 years of age to alienate or sell some of their assets before being eligible for government income support if they have assets worth over \$150,000 (Feigin et al. 2006). A number of iwi and Māori groups individually and collectively own significant assets, so it is important that they not be disadvantaged by mechanisms to secure income or assets related to Te Tiriti o Waitangi settlements.

## National Stroke Management Guidelines

In the best practice guidelines for stroke management in New Zealand there is no mention of the place of the Te Tiriti o Waitangi, and therefore what rights are accorded to Māori and what obligations are placed on the Crown to improve Māori health status and Māori outcomes related to stroke. Best practice needs to be based on a full understanding of such issues as why Māori have a lower incidence of stroke but die earlier from heart disease or smoking. Current guidelines for stroke need to be reviewed and evaluated regularly to ensure an informed focus on reducing health disparities between Māori and Pākehā (Stroke Foundation New Zealand 2003).

### Stroke Services

Both Māori stroke survivors and their caregivers identified the need for more help from hospital- and community-based health services to provide information and support. Together, both groups had to find their own way in negotiating and managing an appropriate stroke rehabilitation process. Crucially, survivors and caregivers wanted information to provide them with a reference point to assess how well they were doing in terms of recovering from stroke, and whether they were making progress in relation to expected outcomes. Stroke survivors who had diabetes and were being managed by hospital services seemed to have better access to support. Information provided by the Stroke Foundation was appreciated, and it was identified that this organisation provided positive assistance.

### CONCLUSION

The findings from this study are important. Although the number of participants is small, the interviews with Māori stroke survivors and their primary caregivers provide insight into how Māori see and manage a stroke event. Findings from this study cannot be generalised to represent the experience of all Māori stroke survivors. However, information highlights the need for stroke management in New Zealand to be more specific in relation to Māori, to monitor whether current health disparities between Māori and Pākehā are being reduced, and to ensure that Māori are not discriminated against for their health status and assets that they have had or reclaimed as tangata whenua.

Stroke is an important instance of health disparities that exist between Māori and Pākehā, and is a reference point to monitor if positive health changes are occurring for Māori. Also, information from these interviews, along with other ethnic interviews, has provided the basis for developing a questionnaire to collect quantitative data from all individuals who experienced and survived a stroke six months after the event and

were part of the 2002/2003 study. Results from this questionnaire are likely to provide additional information on the difference in health outcomes for different ethnic groups in New Zealand as a result of a stroke event.

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