

THE FUTURE HEALTH CARE CONCERNS AND
EXPECTATIONS OF LOW INCOME WOMEN IN
WELLINGTON, NEW ZEALAND AND ST JOHN'S, CANADA

...IRE FOR NEWFOUNDLAND STUDIES

**TOTAL OF 10 PAGES ONLY
MAY BE XEROXED**

(Without Author's Permission)

PENELOPE SALMON



**THE FUTURE HEALTH CARE CONCERNS AND EXPECTATIONS OF LOW
INCOME WOMEN IN WELLINGTON, NEW ZEALAND AND ST JOHN'S, CANADA**

by

© Penelope Salmon

A thesis submitted to the School of Graduate Studies
in partial fulfilment of the requirements for the degree of
Master of Science

Department of Community Health, Faculty of Medicine
Memorial University of Newfoundland

December 2005

St John's

Newfoundland



Library and
Archives Canada

Bibliothèque et
Archives Canada

Published Heritage
Branch

Direction du
Patrimoine de l'édition

395 Wellington Street
Ottawa ON K1A 0N4
Canada

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file *Votre référence*
ISBN: 978-0-494-19394-5
Our file *Notre référence*
ISBN: 978-0-494-19394-5

NOTICE:

The author has granted a non-exclusive license allowing Library and Archives Canada to reproduce, publish, archive, preserve, conserve, communicate to the public by telecommunication or on the Internet, loan, distribute and sell theses worldwide, for commercial or non-commercial purposes, in microform, paper, electronic and/or any other formats.

The author retains copyright ownership and moral rights in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

AVIS:

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque et Archives Canada de reproduire, publier, archiver, sauvegarder, conserver, transmettre au public par télécommunication ou par l'Internet, prêter, distribuer et vendre des thèses partout dans le monde, à des fins commerciales ou autres, sur support microforme, papier, électronique et/ou autres formats.

L'auteur conserve la propriété du droit d'auteur et des droits moraux qui protègent cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

In compliance with the Canadian Privacy Act some supporting forms may have been removed from this thesis.

Conformément à la loi canadienne sur la protection de la vie privée, quelques formulaires secondaires ont été enlevés de cette thèse.

While these forms may be included in the document page count, their removal does not represent any loss of content from the thesis.

Bien que ces formulaires aient inclus dans la pagination, il n'y aura aucun contenu manquant.


Canada

ABSTRACT

There is much discussion about the potential impact of a growing ageing population on health care. It is argued that there will be demands for increased health funding as resources are stretched to cover increasing numbers of seniors accessing the health care system. This research investigated the future health care concerns and expectations of low income women in Wellington, New Zealand and St John's, Newfoundland and Labrador, with a view to informing future health care policy for this age group in their senior years. The research also investigated similarities and differences in the women's accounts. The interviews were transcribed and subjected to thematic analysis. Results revealed that the women not only talked about health care, but also about family, community and ageing. The accounts were more similar than different, but areas of difference reflected provision of health care. The findings were interpreted using ideas from narrative psychology.

ACKNOWLEDGEMENTS

I would foremost like to acknowledge and thank my supervisor Dr. Michael Murray for his valuable supervision, direction, guidance, feedback and positive encouragement through-out my studies and for the invaluable financial assistance provided through the *Norms and Narratives* study. Thank you too to my supervisory committee, Dr. Daryl Pullman and Dr. Evan Simpson for their expert guidance and feedback.

I would like to acknowledge all the women I was fortunate enough to talk to through this research. I so much appreciated their honesty and time. All your stories have left lasting impressions on me.

Thank you enormously to my long-suffering husband Mike Salmon for agreeing to move halfway across the world so I could complete this degree and for his enduring patience during this entire time. I especially acknowledge his continual and unconditional support, encouragement and understanding during the completion of the thesis. For the same reason, I would also like to thank my parents Lesley Ennor, Wayne Spencer, Brian Ennor, my parents in-law John and Julie Salmon, and the rest of my family. Thank you to Mum and Brian for their financial support.

I am extremely grateful to my employers Michele Grigg and Helen Glasgow at The Quit Group, for their huge support and commitment in helping me to complete my thesis.

I would like to thank my friends in the Division of Community Health, especially Ayumi Goto and Megan Hayes, whose feedback and encouragement both in St John's and over the email have kept me motivated. I would like to acknowledge my New Zealand friends for always asking me how things were going and for listening to me when I needed to talk about the thesis. I especially want to thank Juliet Corney for her editing assistance, and Darrin and Andrea Hodgetts for their support, for always believing in me and presenting me with this amazing opportunity in the first place.

Finally I would like to thank Sammy, Coco and Kat for keeping me company all those long days, nights and weekends. While I couldn't keep your input and revisions, I appreciate the thought. Oh, ok then, just one in honour of you: bhjnnihyj32hg/kjk.

TABLE OF CONTENTS

Abstract.....	ii
Acknowledgements.....	iii
Chapter 1 Introduction	1
1.1 Introduction.....	1
1.2 Literature Review.....	5
1.2.1 Determinants of Health and Health Inequalities	6
1.2.1.1 Low Income in Canada and New Zealand.....	11
1.2.1.2 Low Income and Women	14
1.2.1.3 Women’s Experiences With Health Care.....	16
1.3 The Context of Health Care in New Zealand and Canada.....	17
1.3.1 The Social Context of Newfoundland and Labrador and New Zealand.....	25
1.3.2 Health Spending in Canada and New Zealand	28
1.4 A Growing Ageing Population	29
1.5 Summary	33
1.6 Aims.....	34
Chapter 2 Method	35
2.1 Design	35
2.2 Participants.....	36
2.3 Procedure	38
2.4 Interviews.....	40
2.5 Interpretation and Analysis.....	41
2.6 Personal Reflection.....	44
Chapter 3 Results	47
3.1 Difficulty Thinking About the Future.....	47
3.2 Expectations	50
3.2.1 Expectations for Health Care.....	51
3.2.1.1 Home Care	52
3.2.1.2 Nursing Home Care	53
3.2.2 Family Expectations	55
3.2.2.1 References to the Past and Other Cultures.....	61
3.3 Future Health Care Concerns	66

3.3.1 Health Care System	67
3.3.1.1 Preventive Health Care	69
3.3.1.2 Uncertainty About What Will be Available	71
3.3.2 Income Issues	74
3.3.2.1 Out of Pocket Costs	75
3.3.2.2 Health Care can be Bought.....	77
3.3.2.3 Private Health Care.....	78
3.3.3 Being Treated Differently	82
Chapter 4 Discussion.....	85
4.1 Interpretation Drawing on Principles of Narrative Theory	85
4.1.1 Personal Narratives	86
4.1.2 Community Narratives	86
4.1.3 Dominant Cultural Narratives.....	90
4.2 Implications for Future Health Care.....	93
4.2.1 Overarching Strategies.....	93
4.2.2 Health System Specific Strategies.....	95
4.3 Context of Research	99
4.4 Conclusion	102
References.....	105
Appendix 1.....	125
Appendix 2.....	127
Appendix 3.....	128
Appendix 4.....	129

CHAPTER 1 INTRODUCTION

1.1 Introduction

Health is closely related to position in society (Graham, 1984; Popay, Williams, Thomas & Gatrell, 1998; Wilkinson, 1996). Research findings repeatedly show that those on low incomes suffer from higher morbidity and mortality rates in every major disease and death group than wealthier people (Leon & Walt, 2001; Lott & Bullock, 2001; Marmot, 2000; Ministry of Health, 2002a; Raphael, 2001; Pearce & Davey-Smith, 2003; Wilkinson, 1996). In fact, a clear gradient exists such that each socio-economic group in developed societies enjoy a healthier, less illness-ridden existence than the group below them in the hierarchy (Federal Provincial and Territorial Advisory Committee on Population Health [FPTACPH], 1999; Ministry of Health, 2002a; Siegrist & Marmot, 2004; Wilkinson, 1996).

Income distribution has been shown by different research groups to be related to national morbidity rates in both developed and developing countries (Wilkinson, 1996; Siegrist & Marmot, 2004). A society that has less equal income distribution has poorer overall health than those societies that have a more equal income distribution (Raphael, 2001; Wilkinson, 1996). It has been found that life expectancy is higher in countries where poorer people receive a higher share of the total income (Kunitz, 2001; Wilkinson, 1996). In developed countries the gap between the richest and poorest people is widening and poverty is becoming especially concentrated in women, visible minorities

and immigrants (Graham, 2001; Leon & Walt, 2001; Lott & Bullock, 2001; Marmot, 2000; Raphael, 2001). This is despite advances in medical science, increases in health care spending and overall rises in the living standards of people in these countries (Leon & Walt, 2001; Siegrist & Marmot, 2004; Wilkinson, 1996).

The above is true in New Zealand and Canada. While both countries enjoyed a relatively equal distribution of wealth for the majority of last century, they have now turned to less equitable distribution of wealth (Scott, 1999; Wolfson & Murphy, 1998). In both countries, those on low incomes have poorer health outcomes overall than more advantaged people (Ajwani, Blakely, Robson, Tobias & Bonne, 2003; Canadian Research Institute for the Advancement of Women [CRIAOW], 2002; FPTACPH, 1999; Graham, 1984, 2001; Health Canada, 2001; Ministry of Health, 2002a; Raphael, 2001; Wilkinson, 1996; Wuest, Merritt-Gray, Berman & Ford-Gilboe, 2002)

The New Zealand government has stated their commitment to reducing inequalities in health (Ministry of Health, 2000), as has the Canadian government as a result of the outcomes of the Romanow commission (Health Canada, 2004a, 2004b, 2004c). Provincially, the Newfoundland and Labrador government has also stated that as part of its health strategy, policies will be developed that will reduce the difference in health associated with low income, gender and age (Department of Health and Community Services, 2002).

The research conducted for this thesis falls under a major national Canadian study, the *Norms and Narratives* study (Murray, Pullman & Heath Rodgers, 2003). The aim of this study is to explore the core moral norms and guiding social narratives related to health

care among the major ethno-cultural sub-groups within Canada's baby boom population, or those born between 1946 and 1964. The New Zealand and Canadian governments are preparing for the senior years of these baby boomers. Given that the baby boomers are coming into their senior years, higher numbers of seniors are going to draw on health care services and as a result increased funding will be needed to provide the same level of service (Ministry of Health, 2003; National Advisory Council on Aging, 2002).

The *Norms and Narratives* study explores the character of beliefs and expectations about the organisation and delivery of health care, the range and availability of health services, and emerging ethical issues in health care that may impact on the needs and expectations of those moving into their retirement years. As social policies, services and products should be designed to meet the needs of those for whom they are intended, it is important that their beliefs and values are understood. Working collaboratively with health care policy makers and advisors, health care administrators, service providers and consumer representatives, the project has a view to informing social policy for the future. While the *Norms and Narratives* project focuses on sub-groups of Canadians, an opportunity arose to also examine what New Zealanders think about the issue of future health care in a New Zealand context.

The particular focus of this research is concerned with identifying the concerns and expectations that the sub-group of low income women in New Zealand and in Newfoundland and Labrador, Canada have for their future health care. The research is focused primarily on women in two urban settings: Wellington, New Zealand and St John's, Newfoundland. Comparing the views of women from these two cities presents a unique opportunity to identify similarities and differences in the health care experiences

of low income women in different urban settings and analysing the findings can provide insights to see what is working, and what is not, in the health care systems of New Zealand and Newfoundland and Labrador for low income women. Further, the research endeavours to provide insights into how the respective health systems can provide health care to these women once they reach retirement age.

Low income women were chosen as low income and gender are two of the most important determinants of health. This is shown by the fact that people living on low incomes have higher illness and mortality rates than wealthier people in our communities. For women specifically, traditional roles that place women as family caregivers, child bearers and subsistence providers can restrict access to education, well paying employment opportunities and health care. Many of these well paying jobs also offer pension (Canada) or super (New Zealand) schemes and health insurance benefits. When women cannot access education and good jobs they invariably end up living on low incomes, are unable to get ahead and their health suffers as a consequence. Unable to succeed financially during working life, the burden of poverty is carried with them into their senior years. Further, because those on low incomes have poorer health outcomes, unimpeded access to health care is all the more important for this group.

By analysing the experiences and stories of low income women, this research has a wider view to inform policy on health care and ageing. Through this research, it is envisaged that giving low income women a voice in the policy process can help the government better plan and target health care policy and delivery to the future needs of these women. As these women experience the health care system first hand, hearing what they say can show where policy and delivery is lacking and where it is working.

Their concerns and expectations have the potential to guide future health care policy to address the health needs of low income women.

The goal of this research is to examine and compare the future health care concerns and expectations of low income women under 65 years of age in Wellington, New Zealand and St John's, Canada, in order to understand their needs for health care when they are in their senior years, and expose potential barriers to receiving adequate health care.

1.2 Literature Review

Low income is one of the major determinants of health. The 'determinants of health' is the collective label given to the multiple factors that contribute to the health of populations (Health Canada, 1997). The remainder of this chapter begins by presenting a brief history of health inequalities and then discusses health determinants and the role they play in health inequalities. This leads into an overview of theories proposed to explain why certain determinants have such a powerful influence on health. Income statistics and health care experiences of low income adults and women in New Zealand and Canada are discussed in the next section. The context of health care in Canada and New Zealand is then presented. The chapter finishes with a review of research on the impact of an ageing society on New Zealand and Canadian society.

1.2.1 Determinants of Health and Health Inequalities

The study of health inequalities is not new. Rediscovering inequalities in health has occurred at various times in our history (Blaxter, 1997; Graham, 2001; Gwatkin, 2000; Leon & Walt, 2001). Studies go back as far as the 19th century with Farr's support for public policies to alleviate poverty (Gwatkin, 2000) and Chadwick's report on the sanitary conditions of the labouring population (Blaxter, 1997). The current interest however began in the early 1970's. It is apparent that despite rises in the overall standard of living after the epidemiological transition for members of developed countries, social and material conditions continue to cause more ill health for poor people (Wilkinson, 1996).

The determinants of health model help us to understand the processes that cause health inequalities. They are a complex and varied combination of factors. Different models and determinants are cited in the literature. However, most include: general socioeconomic and environmental conditions; gender; culture; living and working conditions; social and community influences; health services; individual lifestyle factors; and age, sex and hereditary factors (Dahlgren & Whitehead, 1991; Ministry of Health, 2002a; FPTACPH, 1999; Wuest et al., 2002). Age, sex and hereditary factors are largely unchangeable. However, we have more control over the remaining determinants, and it is widely accepted that these broader social, economic and political determinants exert a powerful influence over the health of populations.

Lifestyle or behavioural risk factors such as smoking, exercise and diet, have been the most recognised and studied determinants considered to contribute to one's health, or

lack of, and have been the dominant focus of intervention strategies to improve health. However, it is widely accepted that it is social and economic factors, and not lifestyle factors, that are the leading risk factors in a variety of illnesses (Ajwani et al., 2003; Graham, 2001; Health Canada, 2001; Ministry of Health, 2002a; Raphael, 2001; Popay & Williams, 1996; Popay et al., 1998; van Kemenade, 2003; Wilkinson, 1996; Wuest et al., 2002). In attempting to separate confounding variables, single factor, quantitative studies disconnect people from their social and sometimes biological environments and ignore the wider context of place (Popay et al., 1998; Wilkinson, 1996). Health is affected by a complex combination of social, political, environmental and economic conditions, and focusing only on individual risk factors ignores the complex interaction of factors that contribute to health inequalities (Pederson, 2001; Popay et al., 1998; Wuest et al., 2002).

Two major approaches that examine how health inequalities arise, and which this section focuses on, are social capital and the life course approach. A unifying factor between these two approaches is the role of psychosocial effects.

Researchers in the social capital area concur that the quality of the social life in a community is one of the most powerful determinants of health and that social capital is the key to health in communities (van Kemenade, 2003; Wilkinson, 1996). The effect of social capital on health has been demonstrated through studies linking mortality and morbidity rates with measures such as social networks, social links, social integration, social trust and civic participation (van Kemenade, 2003; Wilkinson, 1996). These researchers argue that communities with higher social capital have better economic and social performance and better health outcomes than those with low measures of social capital.

While the statistical link between measures of social capital and health outcomes are well documented, the mechanisms underlying these links are less understood. Wilkinson addresses this gap in understanding by explaining that social capital impacts on health inequalities in two ways – by the effect of relative poverty and through psychosocial pathways. He describes research findings that show countries with the largest gap between rich and poor people are countries with the poorest health and as Wilkinson theorises, the lowest social capital. He argues that income inequalities within countries influence morbidity and mortality rates through determining the strength of the impact of relative deprivation on health. Relative deprivation occurs when some members of a community have less than others do, and are therefore going without. Wilkinson theorises that what matters is not having the best modern consumables, such as a new car or the latest television, but what owning these items mean socially and how it makes a person feel about themselves and the world around them. Such relativities remind people about their social position and devaluation as a person and it is this income inequality, rather than absolute levels of income, that impact on health (Alleyne, Casas, & Castillo-Salgado, 2000; Marmot, 2000; Wilkinson, 1996).

These feelings, combined with the limited options that those on low incomes experience, lead to stress. The stress caused from living in poverty can influence health through a low sense of control and self esteem, depression, anxiety, worries, concerns, and economic and other insecurities. Chronic stress then leads to physiological processes affecting endocrine and immunological processes and which increases susceptibility to disease (Graham, 1984; 2001; Marmot, 2000; Siegrist & Marmot, 2004; Wilkinson, 1996). Wilkinson suggests that these negative emotions are translated into antisocial

behaviour and decreased participation in the community. Further, stress-induced behaviours, for example smoking, also result in poorer health outcomes (Graham, 1984; Wilkinson, 1996). In addition, poor housing and malnourishment increase susceptibility to communicable diseases, impacting negatively on health (CRIAOW, 2002; FPTACPH, 1999; Graham, 1984, 2001; Leon & Walt, 2001; van Kemenade, 2003).

Several authors, however, have critiqued Wilkinson's social capital thesis. Kunitz (2001) reviews studies that have found both positive and negative effects of social capital. He argues that the complex nature of social networks makes for ambiguous findings, and depends on the quality, structure, function and effectiveness of social networks and the effect they have on people's health. This is especially so for women. Although women are found to use support networks more than men, women also provide more support.

Additionally, focusing on the causal pathways from the social environment to health defines income inequality as an individualised, psychological problem rather than a social problem (Denny, 2002). Focusing solutions on addressing social capital may be ineffective because such approaches lead to victim blaming at the community level and ignore the health effects caused by macro level social and economic policies (Pearce & Davey Smith, 2003). While Pearce and Davey Smith do acknowledge that psychosocial pathways play a role in increasing health inequalities, they state these are just one aspect of potential pathways between macro-level forces and health. Instead, income inequality, social capital and health in a community may all be consequences of social and economic processes that influence health across the life course. Pearce and Davey Smith suggest that the life course approach is a more robust explanation of how social inequalities affect health.

The life-course approach views biological and social processes as a reciprocal relationship, both influencing the outcomes of each other (Davey Smith, Gunnell & Ben-Shlomo, 2001; Popay et al., 1998). In this approach, health influences are multi faceted and deteriorations in health are the result of a lifetime accumulation of events (Davey Smith et al., 2001; Graham, 2001; Ministry of Health, 2002a; Popay et al., 1998). Material, psycho-social and behavioural exposure to health risks are patterned by socio-economic pathways individuals follow in their lives, which in turn are fashioned by wider social structures of inequality (Graham, 2001; Popay et al., 1998). Wider social processes concentrate the risk exposure in certain people and can be followed from birth to death. The socio-economic status of a person's parents determines birth weight, nutrition and lung development all of which have been found to influence future health prospects. Further through primary socialisation, the parent's social conditions affect the life chances of their children, for example through access to educational attainment to secure good employment (Graham, 2001; Popay et al., 1998; Siegrist & Marmot, 2004). During working life this theory moves beyond individual incomes to social structures that point to ways in which occupational opportunities shape the lives and life chances of individuals and their families (Graham, 2001; Popay et al., 1998; Siegrist & Marmot 2004). Pearce and Davey Smith (2003) further report that many studies have demonstrated that deprived circumstances in childhood increase a person's risk of poor health outcomes later in life, no matter what their socio-economic status is later in life.

Overall, the life course approach shows it is not where a person is in the social structure that matters, it is how their position shapes exposure to health damaging influences across people's lives (Graham, 2001). The life course approach points to where the

biological, economic, social and psychological risk factors interact and it reveals critical periods in people's lives where policies can be implemented that will protect and defend people against an accumulation of risk (Graham, 2001; Pearce & Davey Smith, 2003; Popay, et.al., 1998).

In sum, the two approaches described above aid our understanding of how inequalities in communities affect health. The two approaches do agree that low income causes poorer health outcomes and more generally that wider social factors contribute to income inequalities and therefore health inequalities. They also show that health inequalities involve more than just low-income, and that psychosocial factors also play a role (Marmot, 2000). However, their contrasting viewpoints also highlight the controversy surrounding pathways from social to health inequalities and how they should be addressed, either through strengthening communities (i.e., the social capital approach) or by changing social and economic structures (i.e., life course). These ideas will be revisited in the discussion. This chapter now presents statistics and experiences of low income people in Canada and New Zealand.

1.2.1.1 Low Income in Canada and New Zealand

In Canada poverty is measured in part by Statistics Canada's low-income cut-offs (LICOs) 1992 base. Although not an absolute measure of poverty as such, LICOs identify those individuals and families who are significantly worse off than the average person or family, and have been used by researchers as a measure of relatively deprived groups in Canadian society. The cut-offs are selected on the basis that people

with incomes below the cut-off limits usually spend more than 55 percent of their income on food, shelter and clothing and as a result are deemed to be living in strained circumstances (CRIAW, 2002; FPTACPH, 1999; Statistics Canada, 2005a).

The prevalence of low income after tax in Canada is 9.5 percent. When broken down into subgroups, 39 percent of female lone-parent families are low income compared to 6 percent of two parent families. Women also have a higher prevalence of low income at 10.4 percent compared with 8.8 percent for men. The prevalence is higher for women who are unattached. Unattached women under 65 have a low income prevalence of 26.5 percent compared with 7.6 percent of women in economic families and 10.4 percent for all women under 65 years of age. Senior unattached women are also more likely to be low income. Almost 20 percent of unattached women over 65 years are low income compared to just 2.2 percent of women over 65 years in economic families, and 9 percent of women overall (Statistics Canada, 2005a). Provincially, Newfoundland and Labrador has the highest rate of low income. In 2001, 17.4 percent of Newfoundlanders and Labradoreans were classified as low income (Statistics Canada, 2005b). Furthermore, seniors in Newfoundland and Labrador are the poorest senior group in Canada (Statistics Canada, 1999a).

Before discussing low income in New Zealand it is important to recognise that it is somewhat difficult to compare the rates of low income in New Zealand and Canada absolutely because of variation between how the countries measure low income, reflecting the lack of standardised measures of low income internationally (Leon and Walt, 2001). It is important to bear this in mind when reading these statistics.

In New Zealand there is no poverty line because of methodological issues in deciding where the line should be set. Regional variation of factors such as accommodation costs, short-term low income, seasonal work and how to measure low income over time make setting the line difficult. However, low income households in New Zealand are defined as those in the bottom quintile (lowest 20 percent) of income or those whose income is less than 60 percent of the median (Scott, 1999). In 2002, the median income for New Zealanders was \$18,500, therefore using a measure of 60 percent of the median income would set those earning \$11,100 or less as being low income (Statistics New Zealand, 2002a).

Similar to Canada, low income is concentrated in New Zealand women. The median income for women in 2001 was \$14,500 compared with \$24,900 for men. Low incomes also fall on lone parent, who are more likely to be headed by women (Statistics New Zealand, 2002a, 2002b). Fifty percent of one-parent families earned less than \$20,000 per year, compared with 6 percent of two-parent families (Statistics New Zealand, 2002a). Women represent around 60 percent of those in the two lowest income quintiles (Statistics New Zealand, 2004a). Elderly people in New Zealand are over-represented in low income figures and older men's median incomes are higher than older women's (Scott, 1999; Statistics New Zealand, 2000a).

Income is one of the major determinants of health. As has been described earlier, those living on a low income have poorer health outcomes than those with higher incomes. Therefore, it would be expected that as low income people have poorer health outcomes, they would need extra assistance from the health care system and that the system would be easily accessible to them. Yet, research findings looking at both New Zealand and

Canada have indicated that this is not the case. Research has shown inequalities to accessing health care based on income are apparent in New Zealand and Canada. Low income adults in both countries were more likely to report going without needed care, or experiencing difficulty getting health care when needed, and that these access concerns were related to cost. This included not going to see the doctor, seeing specialists, inability to pay medical bills, difficulty accessing health care after-hours, and difficulty filling prescriptions (Ministry of Health, 2003; Schoen, Blendon, DesRoches, Osborn, Doty & Downey, 2002; Schoen & Doty, 2004). Furthermore, in both countries lower income groups spent a higher portion of their after tax income on health care (Canadian Institute for Health Information [CIHI], 2002; Ministry of Health, 2004a).

1.2.1.2 Low Income and Women

In developed countries such as Canada and New Zealand, women are always over-represented in the lowest income categories (Statistics Canada, 2005a; Statistics New Zealand, 2002a). Women overall earn less income than men and in any industry earn less than men even when their level of education is equal (CRIAW, 2002; FPTACPH, 1999). In fact, women suffer the largest burden of poverty overall (Gupta, 2000; CRIAW, 2002; FPTACPH, 1999; Graham, 2001; Lott & Bullock, 2001). Seventy percent of the world's poor are women (Gupta, 2000). This is also evidenced by the higher proportion of women in both Canada and New Zealand living on low incomes.

That such a disproportionate percentage of New Zealand and Canadian women suffer from higher rates of low income is seen as a result of social, political and economic

factors. Traditional roles position women as family caregivers, child bearers and subsistence providers and these roles can restrict opportunities to access education, meaningful and/or high paying work and access to good health care (CRIAW, 2002; Lott & Bullock, 2001; Lowry, 2002; Wuest et al., 2002). While it is important to recognise that these roles are valuable, women should not have to suffer health-wise or financially to do so.

There is much evidence that documents women's disadvantaged position in the labour market (CRIAW, 2002; Graham, 1984). This disadvantaged position is a result of jobs in the service industry and part time work, work that generally is low paying, insecure and offers little to no health benefits (CRIAW, 2002; Graham, 1984; Lott & Bullock, 2001; Lowry, 2002). Many employed women in Canada and New Zealand continue to work in these situations (Statistics New Zealand, 2002a; Statistics Canada, 2000). Care giving can also economically disadvantage women. Care giving responsibilities at home, be it for children or elderly family members, limit and affect work opportunities outside of the home and reduce earning capacity (CRIAW, 2002; Lott & Bullock, 2001; Lowry, 2002; Reutter, Neufeld & Harrison, 2000).

For women, occupational and material life have implications for long term economic security, health and independence later in life. Low paying and part time work make it harder for women to save for retirement in both countries, affecting economic security in retirement (CRIAW, 2002; Lott & Bullock, 2001; Lowry, 2002; Moen & Forest, 1995). Access to pension plans in Canada is particularly unfair to women. The Canadian Pension Plan (CPP) is based on earnings and because women are paid less overall than men, and because they have care giving responsibilities to family, the benefits women

get from this plan are severely lacking compared to men (CRIAOW, 2002; MacDonald, 1998). In contrast, New Zealand's Superannuation plan gives senior women the greatest income equity with men in their lives (Statistics New Zealand, 2000a). However, senior New Zealand women have a lower median income and this is most likely due to being unable to put money aside for retirement savings during their working years.

1.2.1.3 Women's Experiences With Health Care

In the same way gender differences are apparent in low income rates, so too are gender differences apparent in experiences with health care. Research on women's experiences of and needs for health care repeatedly reveal that women value comprehensive, holistic treatment. This includes attention to not just their physical ailments, but attention to their psychological and emotional health also (Tannenbaum, Nasmith & Mayo, 2003). Caring, respectful, empathetic and open communication is valued by women (Bryant, Corbett & Kutner, 2001; Esser-Stuart & Lyons, 2002; Feldman, 1999; Meadows, Thurston & Berenson, 2001; Taylor & Dower, 1997). However, research evidence reveals a discrepancy between women's emotional health needs and the ability of some doctors to recognise and respond to these needs (Tannenbaum et al., 2003). Studies often describe that women want to be active participants in their health care encounters (Tannenbaum et al., 2003; Taylor & Downer, 1997).

As well as not feeling valued, accessibility to health care can act as a barrier for women seeking health care. Studies have described waiting times and difficulty getting appointments to see health professionals as major hindrances to accessibility to health

care (Schoen & Doty, 2004; Tannenbaum et al., 2003, Tannenbaum & Mayo, 2003; Taylor & Downer, 1997). Women describe overworked medical staff and the implications this has for reducing the quality of their health care interactions (Meadows et al., 2001; Tannenbaum et al., 2003). Women also describe having doctors take the time to listen to women's concerns as important (Meadows et al., 2001; Tannenbaum et al., 2003, Tannenbaum & Mayo, 2003; Taylor & Downer, 1997).

1.3 The Context of Health Care in New Zealand and Canada

New Zealand and Canada have publicly administered, universal systems (universalism). Universalism refers to the provision of programmes, services and funding for all citizens. Such systems have the benefit of promoting a sense of belonging and entitlement, which increases social cohesion and inclusiveness (Crampton, 2002). This is particularly strong in Canada where it is often heard that their health system is part of being Canadian. Universal systems are designed to avoid stigmatising minority groups and avoid the need for expensive targeting mechanisms. However, on the downside, universalism can cause 'middle-class capture' where more well-off and resourced people end up accessing and benefiting the most from the health system (Crampton, 2002). Further, programmes can be designed for the majority group therefore becoming less relevant and applicable to the needs of other groups. However, both New Zealand and Canada employ targeting and population based funding to deliver health care to more at need populations (Crampton, 2002; MacDonald, 1998).

Although New Zealand and Canada employ universal systems, the histories of the development of their systems are quite different. New Zealand's health sector and the health care system it administered remained relatively stable and unchanged for the half century since its formation in the 1940s/50s and, although not without problems, was supported by both major political parties (Gauld, 2001). However, with the return of the National Party to Parliament in the early 1990s New Zealand's health system has undergone incessant, often controversial, change (Davis & Ashton, 2001; Gauld, 2001). The changes began in 1991 with the formation of the competition driven Regional Health Authorities and Crown Health Enterprises. Essentially these organisations meant a more business like approach for public providers whereby funding and purchasing and provision of health services were kept separate, and hospitals were expected to earn a rate of return capital like that of businesses in the private sector (Davis & Ashton, 2001; Devlin, Maynard & Mays, 2001; Kriebel, 2000). However the experiment with the 'quasimarket' model did not work because the model emphasised production and profits, and attention to the quality of services and their affects on health outcomes was somewhat lost (Devlin et al., 2001).

In 1999 under the Labour government, the system went full circle and the funding and purchasing agencies were reamalgamated into 22 District Health Boards. The key components of the new system were structural changes that removed the purchase-provider separation and strengthened local, democratic input into decisions about health care, and secondly, development of strategies that guided the system (Davis & Ashton, 2001; Devlin et al., 2001; Gauld, 2001; Ministry of Health, 2003).

The New Zealand Health Strategy was released in December 2000, followed shortly thereafter by the Primary Health Care Strategy in February 2001¹. The Primary Health Care Strategy is implemented locally through Primary Health Organisations (PHOs). Being enrolled with a PHO is intended to provide patients continuity of health care through building long-term relationships with the PHO and facilitating better co-ordination of health care over the lifetime. Further, funding is allocated to PHOs based on the characteristics of their enrolled populations (population needs based funding). Therefore, PHOs covering very deprived populations will be given extra funding to allow for more free or low cost services (Ministry of Health, 2005a). There is general consensus between the major political parties that no further re-structuring will be conducted and that any changes now made will reduce co-payments for GP consultations and pharmaceuticals, leading to a shift towards a more universal health system (Ashton, Mays & Devlin, 2005; Kriebler, 2000). New Zealanders seem to be supportive of the new direction of health care (Health Reforms 2001 Research Team, 2003), but many continue to express concern about health care privatisation, despite private provision of health care being part of the New Zealand health care system since the 1950s (Kriebler, 2000).

¹ The New Zealand Health Strategy is based on seven fundamental underlying principles. These principles are applied across the health sector and are supposed to be reflected in any new strategies or developments made:

- Acknowledging the special relationship between Maori and the Crown under the Treaty of Waitangi.
- Good health and wellbeing for all New Zealanders throughout their lives.
- An improvement in health status of those currently disadvantaged.
- Collaborative health promotion and disease and injury prevention by all sectors.
- Timely and equitable access for all New Zealanders to a comprehensive range of health and disability services, regardless of ability to pay.
- A high-performing system in which people have confidence.
- Active involvement of consumers and communities at all levels (Ministry of Health, 2000)

The health care reforms in New Zealand attracted much international attention (Devlin et al, 2001). Certainly, no other country has implemented so much change in such a short amount of time as New Zealand has (Gauld, 2001), unlike Canada whose health care system remains true to the principles it was founded on in the 1960s and is largely unchanged.

Universal hospital and medical insurance were adopted by the Canadian provinces from 1961 after the federal government offered to pay 50 percent of provincial hospital and medical costs (Iglehart, 2000; Mulder, 2001; Naylor, 1999; Vayda & Deber, 1984). However, the costs to the federal government spiralled out of control and in 1977 the federal government passed Bill C-37 limiting federal funds and making the funds independent of provincial expenditure, meaning the provinces had to meet the excess costs themselves. Problems with this bill led to confrontations between federal and provincial governments and within provinces between government and local health providers (Vayda & Deber, 1984).

In 1984 the Canada Health Act was passed. It is Canada's federal health insurance legislation. This Act built on the five principles of the original provincial plans.² Its aim is to ensure all that residents of Canada have reasonable access to insured services without direct charges, and it embodies a commitment to equality, fairness and access based on need and not ability to pay (Health Canada, 2004c, 2004d, 2004e; Naylor,

² The five principles of the Canada Health Act are: Universality, Accessibility, Portability, Comprehensiveness and Public Administration (Health Canada, 2004e).

1999). This act also banned the practice of extra billing emphasising commitment to a publicly funded service that provides equal access to everyone regardless of income (Inglehart, 2000; Naylor, 1999). The role of the federal government is to be the guardian of the health system's shared interests and values (Health Canada, 2004d). The federal government provides funding assistance to the provinces and territories through health funding transfers. From there it is up to the provinces and territories how they deliver health care to their populations (Health Canada, 2004d). How they do it depends on the demographic make up of their populations, the geographic spread of their residents and the particular needs of their populations (CIHI, 2004).

At the present time the provincial and federal governments are addressing the issues of keeping the Canada Health Act and Medicare sustainable into the future. One of the major challenges is how to keep the health care system sustainable while maintaining the values of the act that Canadians strongly believe in (Romanow, 2002). Public support for the provision of public health care is particularly strong in Canada, where it is often mentioned that the Canadian health system is part of Canadian's national identity (MacDonald, 1998; Murray, 2004; Naylor, 1999). However, there is evidence of a decline in satisfaction with the Canadian system and that more Canadians are expressing concern about the potential for changes to their health care system. While satisfaction with the Canadian system remained high for many years, surveys and research have shown declining satisfaction and confidence with the system over the last decade (Blendon, Schoen, DesRoches, Osborn, & Downey, 2002a; Boychuk, 2002; Mulder, 2001). Interestingly, New Zealanders reported increasing satisfaction with their system over the same time period, possibly reflecting the new direction of health care in that country (Schoen et al., 2002). However, low income adults in both countries expressed

lower satisfaction with their health care systems than higher income adults (Blendon et al., 2002b).

To address the increasing discontent with the Canadian system and its sustainability into the future, Roy Romanow (2002) was commissioned by the Government of Canada to “carefully examine the state of public health care in [Canada] and recommend ways it could be made sustainable into the 21st Century” (p.1). The process under which Romanow undertook his consultations is an excellent example of community consultation. In his undertakings, Romanow and his team met with Canadians from many communities, experts, advocates, premiers and government leaders and listened to what they had to say about the future of their health care system.

Romanow reported recognition that health care has changed since Medicare was introduced 40 years ago, particularly around home care and pharmaceuticals. Needs have also changed with disparities in access and health outcomes evident in populations such as Aboriginal peoples and low income adults, and difficulties in meeting the needs of an ageing population (Health Canada, 2004a, 2004b, 2004d; Romanow, 2002). In September 2004, as a result of Romanow’s report, the First Ministers of Canada agreed to the 2003 Accord on Health Care Renewal. The Accord is an action plan to renew and sustain publicly funded health care into the future, and to reform the system and make it

more accountable to Canadians³ (Department of Health and Community Services, 2004; Health Canada, 2004b).

In the same way the development of the Canadian and New Zealand systems differed, so too do certain areas of provision. One major area of difference between the two systems is that private insurance for services covered by both the public and private providers is permitted in New Zealand. Law in Canada prohibits private provision of health care, although private insurance is permitted for use to benefits covered by the public system only (Ministry of Health, 2004a; Schoen & Doty, 2004).

However, despite private provision of health care being prohibited by law in Canada, many have felt that private provision of health care has already made its way into the Canadian health care system. It is occurring through a shift to private responsibility for health and through cuts to publicly funded care that are being picked up by private providers and paid for by the public out of their own pockets (Armstrong, 2002). Additionally, Canadians do express concern about the potential for privatisation of their

³ The First Ministers' Accord on Health Care Renewal agreed on the following action plan based on the following principles:

- universality, accessibility, portability, comprehensiveness, and public administration;
- access to medically necessary health services based on need, not ability to pay;
- reforms focused on the needs of patients to ensure that all Canadians have access to the health care services they need, when they need them;
- collaboration between all governments, working together in common purpose to meet the evolving health care needs of Canadians;
- advancement through the sharing of best practices;
- continued accountability and provision of information to make progress transparent to citizens; and
- jurisdictional flexibility (Health Canada, 2004b).

system and there is only lukewarm support for provision of private health care in Canada (Naylor, 1999).

While the countries differ in whether private provision of health care services are permitted, both countries do allow residents to take out private health insurance to cover the costs of health care. In 2002, 35 percent of New Zealanders were covered by private insurance (Ministry of Health, 2004b). Statistics on those who have private insurance in Canada are broken down by service type. Sixty-two percent of Canadians have hospital insurance, 76.5 percent have prescription medication insurance, 62 percent have dental and 55 percent eye glasses and contacts insurance (Sanmartin, Ng, Blackwell, Gentleman, Martinez & Simile, 2004)

A second area of difference is that the Canada Health Act only applies to physician and hospital services, and prescription drugs coverage is mostly limited to elderly and low income people, and then only under certain criteria (for example income). This is in comparison to New Zealand where prescription drugs are covered by the public system (Schoen & Doty, 2004). Home and nursing home care is not required to be provided by Canadian provinces, and provision of these services and funding for them varies greatly between provinces (Iglehart, 2000; Naylor, 1999). Again, this is in contrast to New Zealand where home care is provided by the public system (Ministry of Health, 2004a).

In New Zealand residents are expected to cost-share many services including physicians fees and other services (Ministry of Health, 2004a; Schoen & Doty, 2004). Although provision varies by province, across Canada there is no cost-sharing for physician services or hospital costs (Health Canada, 2004d; Schoen & Doty, 2004).

Research findings have indicated that cost-sharing of physician care, user charges, and private provision of health care are creating financial barriers to accessing care in New Zealand and that having private insurance facilitates access to care (Schoen et al., 2002; Ministry of Health, 2004a). It appears that private insurance facilitates access to care in Canada also, and there are income discrepancies in both countries over who has private insurance, with higher income adults being more likely to have health insurance (Ministry of Health, 2004c; Schoen & Doty, 2004). Seventy-nine percent of high income compared to 36 percent of low income Canadians, and 60 percent of high income compared to 24 percent of low income New Zealanders, reported having private insurance (Schoen & Doty, 2004).

1.3.1 The Social Context of Newfoundland and Labrador and New Zealand

It is important to consider the wider societal context within which the respective health care systems are situated. The province of Newfoundland and Labrador has experienced a crisis due to a moratorium on the groundfish industry since 1992. The collapse of the cod fisheries has had a major impact on the economy of the province where the industry has been a major employer of many residents for centuries. Those living in outports,⁴ where fisheries provided the main source of employment through fishing and processing plants, were particularly hard hit (Davis & Gerrard, 2000; Hamilton, Haedrich & Duncan, 2004; MacDonald, 1998). High unemployment has consequently resulted in large scale

⁴ Small coastal communities

out-migration, particularly among younger workers who, because they have stayed at school longer than the generation before them, are more highly trained and skilled. Out-migration has also occurred, but to a lesser degree in the more populated area of the Avalon Peninsular, where the capital St John's is located (Hamilton et al., 2004).

On the flipside, in-migration is occurring where older, retired workers return home and who will draw on health care services (MacDonald, 1998). Coupled with a reduced working population to support older people, in-migration may put even more strain on health care services. Additionally, Newfoundland and Labrador is the poorest province in Canada, has high unemployment and low income rates, and is facing challenges with gradually declining financial assistance from the federal government of Canada for its social services (MacDonald, 1998; Naylor, 1999), although in the past year, there are indications that this may be changing.

While Newfoundland and Labrador have relied on the fisheries, New Zealand is largely an agricultural and forest based economy, and exports of meat, dairy and forestry products contribute largely to the economy. More recently the service sector, for example tourism, is also becoming an important contributor to the economy (Statistics New Zealand, 2002b). However, because of its small population and isolation, New Zealand is vulnerable to major world events and crises in international markets, such as the September 11, 2001 attacks on the United States and the Asian economic crisis in 1997. Further, activities and decisions within world financial, commodity and labour markets, and increasing global competitiveness can also affect New Zealand. Occurrences such as these can have a significant impact on the New Zealand economy and can affect social conditions in New Zealand (Statistics New Zealand, 2002b).

While New Zealand is vulnerable to external happenings, the development of the country's social system has also affected the social climate. The social context of New Zealand is characterised by past welfare reforms and constant change. In fact, New Zealand is often referred to as the 'social laboratory of the world'. The welfare state created from the 1940s onwards in New Zealand was designed to ensure greater security and equity for New Zealanders and was achieved by the provision of public housing, education, health care, social security, industry regulations and import controls. However, since 1984 there have been social reforms each time one of the major political parties has been elected. Changes to the health care system were outlined earlier in this section, but other sectors affected included education, housing and social welfare (social security). Cuts were made to social services and a user-pays environment for social services developed. Tariffs and trade restrictions were removed and internal deregulation and subsequent privatisation of state-owned enterprises occurred (McClintock, 1998; Statistics New Zealand, 2002b). These changes stalled the forward economic progress of New Zealand and during the time between 1984 and 1999 there was record unemployment and health and wealth inequalities widened (McClintock, 1998).

However, since the Labour government was elected in 1999, investments in health, social security, and education and investment in economic development are beginning to pay off with an unemployment rate that is currently the lowest in the developed world (Maharey, 2005), and income inequality stabilising (Statistics New Zealand, 2002b). There is a general sense of optimism reported in the media. However, for a growing number of New Zealanders, falling rates of home ownership, higher housing costs in

proportion to earnings, and inflated rents (Ministry of Housing, 2002; Statistics New Zealand, 2002b), a slow rate of increase in the wage rate (Hall & Scoobie, 2005) and record numbers of low income families using foodbanks (Saunders, 2005) mean the positive spin-offs are not being enjoyed by everyone. This is especially so for those on low incomes.

1.3.2 Health Spending in Canada and New Zealand

In 2002 the Canadian total expenditure on health was 9.6 percent of gross domestic product (GDP) (OECD Health, 2004). Canada's health funding comes from three main sources; public, private and non-consumption.⁵ Public and non-consumption health funding accounted for 70 percent of health funding overall in Canada with private funding therefore contributing 30 percent (CIHI, 2004). Out of pocket costs amount to 49.7 percent of private costs, private health insurance 40.6 percent, and non-consumption 9.7 percent (CIHI, 2004).

Spending on health care varies across Canadian provinces due to geography, health needs, health care organisation, delivery and demographics (CIHI, 2004). The Newfoundland and Labrador government contributed 79 percent of total health funding with the remainder coming from private funding (CIHI, 2004).

The total expenditure in New Zealand on health was 8.5 percent of GDP (Ashton et al., 2005; OECD Health, 2004). As with Canada, New Zealand's health care system is

predominantly publicly funded. In 2002 public funds contributed 78 percent of health funding (Ministry of Health, 2004b). Like Canada also, the proportion of the contribution of private funding has been steadily increasing during the last several decades (CIHI, 2004; Ministry of Health, 2004b). Around 15 percent of the public funding went to private institutions (Ministry of Health, 2002b).

Twenty-two percent of New Zealand's health funding was contributed through private sources. The largest portion of this private funding came from out of pocket costs by New Zealanders (16 percent of total health expenditure), health insurance (6 percent) and not for profit (0.3 percent). Research has revealed that New Zealanders are more likely than Canadians to encounter costs when seeking care. Thirty-five percent of Canadians compared to just 6 percent of New Zealanders had no out of pocket costs (Schoen & Doty, 2004). This is of concern, as out of pocket costs have been identified as a major deterrent to seeking health care (Esser-Stuart & Lyons, 2002). Furthermore, there is evidence that having private insurance protects people from cost-related access problems in both New Zealand and Canada (Ministry of Health, 2004a; Schoen & Doty, 2004).

1.4 A Growing Ageing Population

The proportion of the ageing population has been increasing steadily during the last century mainly due to increases in life expectancy (Donelan, Blendon, Schoen, Binns,

⁵ For example profit generated from auxiliary services such as gift shops and cafeterias

Osborne & Davis, 2000; Jacobzone, 2000; Statistics Canada, 1999b, 1999c; Statistics New Zealand, 2000b). In 2002, life expectancy in New Zealand stood at 81.1 years for women and 76.3 for men (Statistics New Zealand, 2004b). In 2002 in Canada, life expectancy was 82.1 years for women and 77.2 for men (Statistics Canada, 2004).

By 2011 the total proportion of seniors in Canada is projected to increase when the baby boomers (currently 45-55 years old) start turning 65. It has been projected that by 2025 around 21 percent of the Canadian population will be over 65 years old (CIHI, 2004). In New Zealand, projections estimate that by 2018, 15 percent of the population will be over 65 and this will have increased to 25 percent by 2051 (Ministry of Health, 2001, 2003a; Statistics New Zealand, 2000a).

There are a higher number of elderly women than men due to women's higher life expectancy and lower mortality rate (Statistics Canada, 2000; Statistics New Zealand, 2000b; Statistics New Zealand, 2002b). However, although women live longer, they suffer from more chronic disease and disability than men and they will more likely become widowed (Moen & Forest, 1995; FPTACPH 1999; Pinguart & Sorensen, 2002; Statistics Canada, 2000; Statistics New Zealand, 2000b; Tannenbaum et al., 2003; Watkins & Whaley, 2000).

In the formal health care system, people over the age of 65 years are the highest users of health care services due to the normal ageing process (Coory, 2004; FPTACPH, 1999). In addition, seniors on low incomes report significantly higher rates of certain health problems and lower levels of health than more well off senior groups (FPTACPH, 1999). Positively however, over 90 percent of elderly people live in the community and

only a small proportion of seniors are institutionalised, although the proportion of institutionalised seniors increases as seniors approach 85 years and older (Public Health Agency of Canada, 2002; Statistics Canada, 1999b). Around 7 percent of older New Zealanders lived in institutions such as hospitals or retirement homes (Statistics New Zealand, 2005). Most seniors are healthy and many older adults report high levels of health and well-being (FPTACPH, 1999; Public Health Agency of Canada, 2002). In Canada, 66-80 percent of the total care provided to older people is provided by informal caregivers, around 80 percent of whom are women and usually family members (FPTACPH, 1999; Jacobzone, 2000; Lowry, 2002; Public Health Agency of Canada, 2002; Williams, Forbes, Mitchell, Essar & Corbett, 2003).

In the future, the number of elderly people using health care services is going to increase due to the ageing of the 'baby boomers'. This coming of age will require governments to consider how their health care systems are going to deliver health care to this large cohort. Given the higher expenditure on health and disability services for older people, and an increased percentage of older people in the population, more funding will be needed to provide the same level of service in the future (Ministry of Health, 2001).

In reviewing the literature it was found that a split existed between whether or not an ageing population will have detrimental effects on health care systems. Some have argued that the effects of population ageing will not be as challenging as initially thought. The reasons for this view include that the effects of population ageing will be partly offset by an improvement in the health of older disabled people, which may be accompanied by a long-term deinstitutionalisation trend (Jacobzone, 2000). As people are also healthier for a longer proportion of their lives, they need less health care at each age, referred to

as the compression of morbidity (Coory, 2004; Jacobzone, 2000). As increased life expectancy is accompanied by less disability, older people will be able to lead more autonomous lives and will work for longer, which will put fewer pressures on the social system, particularly the health system (Coory, 2004; Donelan et al., 2000; Jacobzone, 2000). The CIHI (2004) also suggests that the effects of population ageing will be manageable within the context of a growing economy. Coory proposes that such arguments about the effects of the ageing population's affect on health care systems are born from 'ideological positions that favour growth in the private sector and seek to contain health expenditure in the public sector' (p. 581).

Jacobzone (2000) cautions however that while older adults enjoy a longer and higher quality of life, such benefits may have additional costs to the health care system, as reduced disability requires timely access to medical care and new technologies. It is these advances in technology and medicine that have been one of the impicators in driving up health care costs (Gauld, 2001; Jacobzone, 2000; Kriebel, 2000; National Advisory Council on Aging, 2002). Additionally, with a growing proportion of elderly people, there will be fewer citizens of working age to support retired populations (Donelan et al., 2000). The Ministry of Health argues that although government savings will be made through decreases in other areas, for example education, it is likely that these will be foreshadowed by extra costs for superannuation payments or pensions (Ministry of Health, 2003).

Whether or not health care costs will increase with an ageing population, outcomes for ageing can be altered in many ways through policy and the health care system. How Canada and New Zealand choose to deal with the increasing ageing population now in

terms of the balance of care, support for caregivers, timely access to quality health care and choices offered to older populations will largely determine the future of ageing societies (Jacobzone, 2000).

1.5 Summary

The literature reviewed has indicated that those living on low incomes experience more health problems and that women are more likely to be low income. As those on low incomes experience more health problems, it would therefore be expected that they would have a greater need of health care. In addition, both societies are ageing such that it would be expected that the health systems will increasingly have to consider the health care needs of those seniors on low incomes, particularly senior women. While both New Zealand and Canada provide universal health systems, the health systems have evolved differently with a greater focus on medical care in Canada and a greater focus on community and primary health care in New Zealand. In addition, New Zealand provides better access to homecare and pharmaceuticals although it also has provision for private health care. This research provides an opportunity to explore how each system is addressing the particular needs of low income women in two aging societies and further, how each system may meet the needs of low income senior women in the future.

1.6 Aims

To examine the future health care expectations and concerns of a group of low income women in St John's, Newfoundland and Labrador, and Wellington, New Zealand;

To identify the health care issues that are important for their future health care;

To consider the policy implications of the findings for the future.

CHAPTER 2 METHOD

2.1 Design

The research employed qualitative methodology. This approach was chosen because it allows for a deeper understanding of the everyday experience of women rather than just a statistical description of their experiences. Denny (2002) is critical of population health researchers who seem unreflexive of the capacity of statistics to model the real world. Although statistical analyses have shown a recurring relationship between income and health that has aided our understanding of health inequalities, statistical analysis is far removed from the complexity of the social processes that produce them (Flick, 2005; Popay et al., 1998). Qualitative research methodology provides insights into these beliefs and values that are difficult to access through quantitative methods. Qualitative methods are embedded in the places people spend their lives and they give researchers an understanding of the cause of health inequalities (Popay et al., 1998). Qualitative research attempts to preserve the context of people's experiences allowing for deeper participant involvement and understanding from their perspective rather than the researchers' standpoint (Chamberlain, 1997; Flick, 2005). It privileges the participant's point of view rather than examining overall population effects or assessing health on a predetermined, structured scale (Chamberlain, 1997). For these reasons a qualitative perspective was thought the best method to collect the information to achieve the aims this research is exploring.

Data collection can take many forms, including formal and informal interviews, observations, and analysis of written materials (Wuest et al., 2002). The data collection used in this research was formal interviews. A journal was also kept by the researcher through the duration of the research and the ideas and memos recorded in it were used in the writing of the thesis.

2.2 Participants

Eleven women were interviewed in St John's, Canada. At the time of their interviews they ranged in age from 37 – 61 years. Tables 1 and 2 summarise the characteristics each women shared about their current living situation, health and other personal information.

Table 1: Characteristics of St. John's participants

NL1	37	Student, Newfoundlander, mother to teenage sons.
NL2	56	Student, Newfoundlander, married.
NL3	54	Administrator, Newfoundlander, single mother.
NL4	56	Unemployed, volunteer. Mother of teenage daughter. Suffers arthritis. Born outside of province, but has lived in Newfoundland for some time.
NL5	56	Immigrated to Newfoundland from Europe. Student. Married with children. Has osteoarthritis.
NL6	61	Retired, volunteer. Single.
NL7	46	Housewife. Married. Adult children. Has diabetes and heart trouble.

NL8	57	Retired. Married. Adult children. Has depression.
NL9	61	Housewife. Married. Mother. Has ear and thyroid problems.
NL10	53	Mother of teenage children. Born outside of province but has lived in Newfoundland for sometime. Breast cancer survivor.
NL11	59	Writer. Married with no children. Has hypertension.

Eight women were interviewed in Wellington, New Zealand. They ranged in age from 38 – 67 years at the time of their interviews.

Table 2 Characteristics of Wellington participants

NZ1	65	Volunteer community worker. Mother. Has chronic arthritis.
NZ2	39	Beneficiary. Mother. Has depression and anxiety.
NZ3	38	At home mum. Involved in a bad car accident some time ago and also has epilepsy. Uses private health care for children and for some health care for herself.
NZ4	67	Retired. Volunteer. Has diabetes, hypothyroidism, B12 deficiency, myocardial ischemia and renal disease.
NZ5	46	Beneficiary. Reported many problems accessing health care to heal a broken wrist.
NZ6	54	Single. Therapist. Ex-patriot recently returned from England to live in New Zealand again.
NZ7	44	Beneficiary. Contact with the mental health system, and also uses private psychiatry services.

NZ8	52	Factory worker. Mother to teenage children.
-----	----	---

The majority of the participants were baby boomers. This is the generation of people who governments are concerned about due to the bulge of seniors that will occur in the future when this cohort turn 65. All but one was under the age of 65.

2.3 Procedure

The sample obtained for this research was largely opportunistic in that women who showed an interest in being involved in the research were interviewed. However some purposive sampling was undertaken in that the research sought out women who were low income and under 65. In St John's, nine of the women were invited to participate through community workers and colleagues at the university in St John's. Two women were approached directly by the researcher.

In New Zealand the recruitment was different. Notices were put up at the Senior's Centre and the Women's Centre in Wellington. Most responded to the notice at the Women's Centre. Such a recruitment method potentially biased the results towards women who had health problems or a higher amount of contact with the health system, as the notice mentioned health care research. It is thought that women may have been more likely to respond if they had something to say about health care. Nevertheless, the women provided valuable accounts that were entirely useful for the focus of the research.

On first contact, the women were told about the research and were asked if they considered themselves to be living on a low income. Low income was self reported. This is because of problems with measuring poverty (as described in the introduction), which can be an arbitrary amount that has little relevance to women. If the women informed the researcher that they were low income, they were invited to participate in the study.

Interviews were held at a convenient location for the women. Written consent was obtained before commencing the interviews. The interviews were tape-recorded with the women's permission and were subsequently transcribed. The women were assigned aliases. Personal details and consent forms were kept separate from the interview transcripts. There was no identifying information on the transcripts.

Although this research was conducted under the umbrella of the larger Norms and Narratives Research study, it diverged substantially from it in that it compared residents of Canada with residents of New Zealand. In view of this difference an amendment to the original Norms and Narratives protocol was submitted to the Human Investigation Committee and separate ethical approval granted for this study (see Appendix 1).

Transcripts were prepared and entered in the nVivo qualitative software programme for analysis.

The accounts were analysed using thematic analysis with some aspects of grounded theory also being utilised. This is further described in Section 2.5.

2.4 Interviews

Semi-structured interviews questioned women on their: health; concerns for their future health care; expectations for future health care; thoughts about what their life would be like after 65; thoughts about what role they saw family and friends playing in health and future health care; experiences with the health system; issues about being low income; opinions about how the community treats older people; thoughts about what retirement meant to them; and thoughts about how they wanted to be treated when over 65.

The questions were written to facilitate discussion and conversation in the area of interest for the research. The interviews generally followed the order the questions were written. However, if women raised a topic earlier or raised a relevant topic not covered in the questions, they were encouraged to continue. Appendix 2 and 3 contains the questions used in the research. The following section (2.5) explains the process through which the questions were written and refined.

Women were offered the choice of interview location. In St John's eight individual interviews and one group interview were held. The group interview was conducted when the participants expressed they would feel more comfortable being interviewed with their peers. However, in analysis, their comments were considered individually. Interviews took place at several locations; one was held at the university, five at neutral community centre locations, two at the women's homes and one at the researcher's home. In New Zealand, eight individual interviews were held. One interview was held at a neutral community centre location, six at the women's homes and one at the researcher's home.

Before undertaking the interviews, written consent to participate was obtained, participants were assured of the confidentiality of their identities and were offered the opportunity to ask questions and clarify any issues. Most interviews lasted at least 45 minutes and although a small number were close, never went longer than one and a half hours.

2.5 Interpretation and Analysis

The accounts collected were primarily analysed using thematic analysis, however aspects of grounded theory were also drawn on. Thematic analysis was appropriate for this research, as the procedure was developed for comparative studies where the groups of interest are derived from the research question, and the research issue is concerned with the social distribution of perspectives on a process (Flick, 2005). Hence in this study, the area of concern is the similarities and differences of the concerns and expectations for future health care of a group of low income women in St John's, Newfoundland and Wellington, New Zealand. Additionally, thematic analysis allows for comparability of the accounts collected by having defined topics to explore, while at the same time remaining open to related views that fall out of these defined topics (Flick, 2005).

Analysis began early on in the research process, even while further interviews were being conducted. This allowed the research to develop, the questions to be further refined and initial potential themes to arise and be further investigated in future

interviews. The questions that were asked at the beginning of the research were changed, but not significantly, to the questions in the final interviews, as new areas not previously considered were raised and questions that were not working were changed, such as prescribed by grounded theory (Chamberlain, 1999) (see Appendix 2 and 3). For example, earlier questions asked for both a negative and positive experience with the health system. This was changed to a more neutral question about general experiences with the health system, where the participant could decide to share any kind of experience. Detailed questioning on nursing and home care were removed as some were leading and replaced with a more neutral question on where the participant thought she might live. If nursing home care was raised, the researcher was then able to explore this with the women being interviewed. A question on what women expected from retirement was also added to get a feel for concerns and expectations not entirely related to health care. Essentially the questions were revised from a rigid, structured interview outline to a more open, semi-structured interview format. This benefited the research to allow the interviewees to guide the interviews more.

In thematic analysis, each account is initially analysed individually (Flick, 2005). In this research each woman's account was individually coded on nVivo following a thorough read-through. Each account was read at least a second time to pick up on anything that was missed through the first read-through. As each account was read, a coding tree was developed. The coding tree was formed by highlighting relevant portions of text and coding each portion according to a theme or category. Transcripts were coded first by eight broad themes; health care system, family, health, income issues, elderly issues, accessibility, and future health concerns. The transcripts of the women from both countries were also compared for similarities and differences. Part way through the

analysis, constant comparison, adopted from grounded theory, was used to further refine and to reveal the relationship between the themes and categories in the transcripts (Wuest et al., 2002). Appendix 4 presents the coding tree used for this research.

This process was undertaken while interviews were still being conducted. It continued until it was felt saturation was achieved. That is, sufficient data was analysed to ensure a full and detailed understanding of the phenomenon was achieved and a full account of it could be presented (Chamberlain, 1999; Flick, 2005). In this research, it was felt saturation was achieved when, although the stories were different, similar themes and categories were arising and that these presented an overall picture of what the women were saying.

Chamberlain also recommends conducting data collection and analysis before conducting a literature search, although he also cautions that it is important to have some initial understanding of the area of interest. He advises that reviewing the literature before data collection may in fact contaminate the emerging theory and shape the analysis with pre-existing ideas and hypotheses (Chamberlain, 1999). However, Wuest et al. (2002) describe the use of existing literature to reveal linkages with the developing theory and thereby increase theoretical sensitivity. In this research an initial literature review was conducted prior to commencing the interviews. However, by the end of the interviewing process, through using existing literature to make linkages with the findings from this research, new directions and ideas emerged. As more literature in these areas were reviewed, new findings were incorporated into the original literature review. This is also part of the thematic analysis process, whereby existing literature allows the

researcher to make inferences and develop storylines from the themes and categories identified (Aronson, 1994).

Mentors reviewed the resulting analysis and agreement on the analysis was reached.

2.6 Personal Reflection

As the author of this research, I consider it important to include personal reflection on the research process. This section has been added to share my thoughts and experiences with the research process.

I enjoyed using grounded theory and found it to be an intuitive process. That the research process be open to alternative directions and findings was felt appropriate for the research conducted. In the developing stages I was conscious about fitting the women in the research into predefined answers and therefore seeking out predefined outcome about what their future concerns and expectations were. While I did not want this to happen, I in fact often found myself doing this without even being aware of it and discovered that I harboured many assumptions when writing my first questions and what I thought I might find in the research. Such assumptions arose around my thinking that the women had actually thought about the future, or were making plans for life over 65, or that they had answers about what they envisaged health systems would provide them with when they were over 65.

Such assumptions can be understood when I examine my own world view and what I bring to the research process, through what Gair (2000) has referred to as a 'socialised' lens. I had been exposed to social messages in New Zealand to prepare for my retirement before I left for Canada. Even though I was only in my late twenties, there was, and still is, a concern that the government will not be able to provide superannuation (or government pension) to seniors in the future. Therefore, I had personally spent time thinking about this issue, albeit not deeply. Further, I spent time with others in Canada who were researching in a similar area to this research topic, and also had been thinking about my own future concerns in the lead up to the interviews. I was also relatively younger than many of the women I was interviewing and, while was not on a high income in Canada, had somewhere in between a working and middle-class upbringing. In contrast, I was employed in a reasonably well-paying job when I conducted the second half of the interviews in New Zealand. Perhaps having a good income, or the promise of one when my study was finished, allows the luxury of being able to think about and plan for my future. Finally, I was talking to Newfoundland women about their health care system from an outsider's point of view.

When the interviews began and I was not getting clear cut answers to my questions, doubt crept in as to whether I was conducting the research properly, or if my initial and revised questions were off track. However, when the analysis was initiated and the themes and categories were being examined, a clearer picture emerged about the women's views on health care over 65. Their views were not explicitly about health care but rather about health care in addition to many other wider factors, such as family, societal expectations and understandings and so on. In fact, the main findings were far different from what I expected I was going to find. I was expecting to receive from the

women a clear cut view of what they wanted when they were over 65. Instead I received rich texts of experiences and beliefs that revealed complex views about their concerns and expectations for the future.

Therefore, while I tried not to go into the research with any preconceived assumptions, invariably I did. Additionally, I was concerned that as a researcher, how did I ensure that I did not take the knowledge offered through the stories of my participants as my own and use them to my own advantage, to present me as the holder of the knowledge and thought. If it was not for the participants these ideas would not have come into existence at all.

Overall, I came to the understanding that what is important is to be aware of the assumptions and the 'lens' you bring to the research. It was important that I be aware of the privilege and responsibility of talking to these women and I was very aware of presenting their accounts in a way that was going to be most beneficial for them.

CHAPTER 3 RESULTS

This research focuses on investigating the concerns and expectations of future health care for women in the urban settings of St John's, Newfoundland and Wellington, New Zealand. Generally, the two groups of women were much more similar in their expectations and concerns about future health care than they were different. In fact, it was surprising how similar their views were. However, when considered in the context of universal systems built on similar values such similarities are not as surprising and differences mainly centred around provision. Expectations and concerns for the future were interwoven with each other and were sometimes based around current experiences. This section presents the concerns and expectations shared by the women and considers the similarities and differences between the accounts shared by women from each country.

3.1 Difficulty Thinking About the Future

Ageing is often discussed biomedically in the literature and the ageing process measured through clinical and functional variables (Bryant et al., 2001; Feldman, 1999). However, what this research has revealed, supporting other studies (Bryant et al., 2001), is that health outcomes and potential health problems are not as big a concern for health care over the age of 65. In fact, only two participants mentioned a specific health complaint as a future concern. Instead, health is a reflection of the lived experience of daily life. People don't always generate a medicalised vocabulary of problems but

instead refer to their own stories of health and what it means to them (Bryant et al., 2001). In this research, the women's stories about themselves, friends and family were used to structure expectations and concerns with the current and future health system and of life over 65.

It appeared difficult for most of the women interviewed to think about themselves in the future and to reflect on what the future may hold both for themselves and health care. This could be explained in part by the research process that treats ageing like an isolated abstract event. Bryant et al (2001) mentions that many studies treat ageing as a 'static entity' observed in a single point in time, but in reality, ageing is a dynamic process. This idea would explain in part how current experiences were used to frame what the women thought about the future, as it was probably hard for the women to think of themselves as being older.

PS: Have you ever thought about your life after 65, how you'd like your life to be?

NZ5: I try not to think about it.

PS: Ok, why?

NZ5: Because I've yet to see anything that's going to convince me that it's going to be better.

Concern about the future for low income women may also centre around the context of their current lives where they can barely get by now, so what use does thinking about the future bring? As NZ5 perceives, things won't be any better then either.

Pinquart and Sorenson (2002) describe three factors that influence thoughts about future needs: event uncertainty, time uncertainty and resource uncertainty. The women in this

study weighed up whether they needed to plan for future support needs, against the likelihood they perceived this happening and whether they had the resources, financial or otherwise, to receive support. The authors report that not planning for the future lessens worry in the present, as the case may be for the women in this research.

NZ7 was one of the only participants to talk about potential health concerns, in contrast to the findings by Meadows et al. (2001), whose participants often raised health issues. NZ7 also reflects that to think about ageing is hard because being older is seen in a negative light by the rest of the community, and that to be young is the desirable existence.

PS: Do you think that, if there's anything that you want to talk about that I haven't asked you yet that you want to share.

NZ7: So it's all about trying to project myself into the future in a way...

PS: Which is hard to do...

NZ7: Yeah, yeah, so some of it's a bit hypothetical, so at least I've told you what theories I have, yeah, so yes I have thought about it. I mean no one really knows what's going to happen to them do they? No, I mean maybe you could even look at your parents and see what's wrong with them and think oh yeah I would probably get that, but it's not the most cheerful thought, anything to do ageing...

PS: Why do you reckon it's hard for people to think about what it might be like to be older?

NZ7: Well I just think it's not a very cheerful subject, yeah, I mean everyone wants to be young and vital and nobody looks forward to being old do they.

NL11 from Newfoundland also brings the negativity of ageing to the fore, noting that to think about being aged is to think about yourself as decrepit.

NL11: It's hard to get your head there, you know. Even though I'm not that far away from it, it's still hard to think that.... well, you.... first of all, you got to try and think yourself sick and that's a hard thing to do. (laughs).

Only a small number of participants spoke of looking forward to what being older had to bring, a finding replicated by Feldman (1999). Feldman states the needs of older women are broader than those provided by the health care system alone. This is evidenced in this research and much of this section discusses these other needs, such as the role of family and community and who will care for them when they are older.

3.2 Expectations

Expectations have been defined differently in the literature. Some studies describe expectations as probabilities or judgements about the likelihood a certain event will happen, others describe values or desires that people express as perceived needs, standards or importance (Oermann, 1999). This study draws on the latter description of expectations as being based on values, with the focus of this research to explore low income women's concerns and expectations for health care in the future in order to identify issues to accessing good health care. Expectations for future care expressed by the women in this research fell under three categories: expectations on the part of the health care system; expectations on the role their family would, or would not, play in their future care; and expectations about ageing. There was a lot of overlap between these areas. Overall, the categories encompass one bigger value or ideal, that being the basic value that you will be cared for in your old age. This will be presented over the course of the following sections.

3.2.1 Expectations for Health Care

Most participants mentioned the importance of health care professionals showing they cared. Replicating findings from other studies, caring, respectful, empathetic and open communication was valued (Bryant et al., 2001; Esser-Stuart & Lyons, 2002; Feldman, 1999; Meadows et al., 2001; Tannenbaum et al., 2003; Taylor & Dower, 1997). The experience of the encounter preceded any medical issues they had. In terms of expectations, the relationship health care professionals have with their patients is of utmost importance.

Being sent home too soon after surgeries was a worry for a small number of the women, with stories highlighting concerns about being able to cope with daily life without any support. However, emotional support was also an important consideration and NZ4's story following a surgical procedure highlights this particularly poignantly.

NZ4: ...and then I think to myself, oh if only I had someone to make me a cup of tea or, it's really cold, and you go to your flat and you're all alone and you've just been through major surgery. But when I had to go and have this cardiogram, and it'll be a bit traumatising, and then I'll come from that and there'll just be no-one to talk to, no-one to make a cup of tea. It's really horrible. I don't honestly think that it's hard that they take some cognising of the psychological and environmental situation that single old people are in when they have surgical procedures or anything.

NL7: Health care generally - just good access to doctors; and, like I said, if I get sick and I had to have major surgery, I do not want to be sent home four hours later. I expect if you're having major surgery, do it the way they did it before. Make sure you're okay to go. Don't just send you home and that's what.... that's what I'd see the health care go back to.

3.2.1.1 Home Care

An area of difference between the women from each city was about how they talked about home care. The need for this was hardly mentioned by Wellington women. This is most likely due to the provision for home and community care for at-need older New Zealanders by the New Zealand government (Capital Coast District Health Board, 2004). This is in contrast to the Newfoundland and Labrador government who do allow for some publicly funded provision of health care for beneficiaries, based on income and assets, but expect residents to bear some, or most, of the costs themselves. The Newfoundland and Labrador home care programme is also not intended to replace informal support by families (Seniors Policies and Programs Database, 2005). Even though some assistance is provided to lower income people, as little as 1.2 percent qualify according to one source (Lowry, 2002), concern over being able to afford home care surfaced in the Newfoundland women's accounts.

PS: What are the important health care system issues that you foresee?

NL4: Well, prejudice against older people is one thing so that they're not allowed that home care. They have less home care allocated to them than people under 65 in this province. Respite care is now disappearing for people who are over 65, so that means their relatives will have a harder time taking care of them and that is also like strictly prejudice against poor people, right, because rich people can afford to get home care.

PS: Do you have any concerns about health care in your future years?

NL8: Well, if and when that happens and if I can afford it, I'll have someone.... some home care come in. That would be my idea...yeah, I think I would prefer that, if I could afford it, right.

The views of women from each urban setting did converge, despite differing provision of home care, in the event that the women were unable to care for themselves. In this case both groups explained formal home care provided by the government was important and especially pertinent for women who have no family, particularly immediate family, to draw support from. Therefore, there was an expectation on the part of the women from St John's that provision would be made for home care and in New Zealand, that the government would maintain home care provision into the future.

NL6: ...if my sister is not able to come to look out for me, then I would like to be able to say, well, somebody will come for me from the health care, if at all possible...And I wouldn't mind staying in my own house providing the financial resources are there for me to qualify for that, right...

PS: What do you think are particular health concerns for low income women?

NZ6: Hmmm, I think in general low income women probably worry, as I do, about being a burden as they get older...knowing that if you broke your hip or something like that, that you could have a carer come in and help you...

Even for those with family, government assistance is important and in fact seen as a right by some.

3.2.1.2 Nursing Home Care

In some of the accounts, stories about ageing were set in nursing homes and hospitals. There are currently few storylines available for women about ageing besides lost youth, denigration, decline and dependence as being the norm for older people (Feldman,

1999). The women drew on these storylines, despite ageing not being accompanied by lengthy hospital stays for most people (Bryant et al., 2001; Feldman, 1999).

Similar to Feldman's and Bryant et al.'s (2001) studies, the nursing home represents the worst aspects of old age including the culmination of decline, burden, loss of dignity, autonomy, and for some loss of independence.

NZ4: ... and I think this is one of the problems for older people, you think of my problems, it involves my heart, my kidneys, my thyroid, my pancreas, it involves all those things, and if they're all in sync and going along all right, I'm fine, I can be fine, I can be productive, I can be healthy and I can look after myself and all those things. But if they're not it's disaster, I'm just looking at a rest home and for me the thought of being in a stinking, urine smelling rest home like some of them are, I've actually nursed quite a few... it was just appalling at the end of your life, seeing your way out the place. And you know, my mother had a very nice rest home but still wasn't, in Palmerston North, but I wouldn't want her life.

Further, like some of the women in Feldman's (1999) study, the memory of caring for a parent brought concerns regarding mental and physical decline to the fore, as NZ4 goes onto describe:

NZ4: ...and I, myself would have preceded her autonomy and allowed her to die at home no matter if it was shorter life or she died suffering as long as she preferred that to going into a home, that was her choice. And I really believe strongly that unless a person is really out of their tree that their autonomy is the most sacred thing that we must respect no matter what.

NZ4 raised the loss of autonomy that can be experienced by older people, and this was also highlighted by NL4.

NL4: I think one problem we have with old people is that doctors respond to the insistent request of relatives by taking away old people's rights, and old people maybe don't want their relatives to be intervening and yet the relatives are so pushy the doctors cave in and start giving the diagnosis to the relatives without the old person's permission...

Generally, it was important to many of the participants to remain independent as long as possible.

NL10: You want to be independent as long as you can...see, this is the whole thing, you know, you grab your independence and you...you know, you just want to keep it as long as you can.

Unannounced inspections of nursing homes that would ensure basic standards are met were mentioned by two participants, and would go some way to alleviate fear of ending up in a 'urine stinking' rest-home. It was also a comment on ensuring that they would receive high quality care that they would be happy with should they need to go to a nursing home when they were older.

Cost of nursing home care was seen as prohibitive in the same way as home care for the St John's women. NL4 explains her thoughts on this.

NL4: And this all done by social policy and it could be changed. That means it can be changed, I think, and also older people.... well, access to nursing homes, I mean, the province subsidises nursing homes that poor people can't afford to go to. There are like Cadillac nursing homes, you know, very highly subsidised by our provincial Department of Health that do not provide access to everybody, just if you have a bank account.

3.2.2 Family Expectations

Participants discussed the role family might play in their care and support when they were older. Peek, Coward, Peek and Lee (1998) describe global versus specific expectations for care for older family members. They explain that global, or social, norms

reflect wider cultural understandings about caring for ageing parents by adult children, whereas specific expectations are the actual outcome of whether aged parents receive care from their children or not. A parent, or in some cases an extended family member, may feel that adult children are obligated to help parents in older age but understand that certain obstacles and circumstances mediate provision of care. They explain that while parents believe that children should care for them in old age, should they need it, when faced with the actual need, parents turn elsewhere for care, either because of their own personal circumstances, that is they can afford to purchase care for themselves rather than burden children, or because of the circumstances or limitations of their own children. The women in this research could not pay for care, so were restricted in their choice about alternative forms of care. Nevertheless, they were divided on the role their children would play in their caregiving in older age.

Some felt that their children should be available for care and support.

NZ8: For me, I would hope that my kids would take me in if I needed, if I couldn't look after myself anymore. It would be hard for me to have to rely on my kids for that care...actually no, I think that's what family is about, you look after each other. If anything happened to them when they were out in the world by themselves, I would take care of them and same goes for them with me...

Initially NL1 was seen to express concern that children would unwillingly be expected to provide care for ailing parents.

NL1: You got people out there who have children and, you know, they've made their lives on the mainland or out in some rural community in Newfoundland, right, and if you're here in the city and you get sick and you come home, is it because you've got family.... well, you have family so we can't provide these services for you so does that mean that my son or your daughter has got to give up their job or to come home because I need that help because I'm the parent, right. They feel obligated to give it to me - the help, right. You

know, like.... but should it... should it go that far or should the health be there to help, you know, for.... like I say, it depends on the circumstances but I do think a family should play a big role in.... you know, with their family member, you know, over 65. I really think you should play a big role if it's possible.

However, NL1 later discloses her expectation to have her own children care for her, with the others in the group agreeing:

NL1: I've thought of that and I guess me again, my own personal thoughts, if I put my life into my children, I think my children owe me, you know, them last couple of years.

NL2: That's right.

NL3: I think so too.

NL1: And I think they will...

Consistent with Peek et al. (1998), several participants, including NL1 above, recognised individual circumstances in their children's lives that may mean they would be unable to provide care. These are the moderating influences, or specific expectations, described by Peek et al. that would affect an adult child's ability to provide care (1998). The following quotes describe these ideas further.

NL8: Now I'm very close to my two sons. Now I don't know what role they would play. I could live to be over 80, right, and here we are, 50. So, I mean, why could they be bound with me at that age, right, and they probably got grandchildren by that time, right, so I don't know.

PS: Do you think they.... like your family should care for you when you're older?

NL10: No.

PS: So what is your view on that?

NL10: (laughs)

PS: If you want to answer of course.

NL10: It's really funny because Dave, my son, he.... (laughs) and he'll say something like, oh, wait until I put you in the home, you know, and then, oh you know, he's so right; and then.... then.... no, like I don't want to be a burden to them and I would hate for them to feel.... if they did it because they wanted to, but I would hate for them to feel obligated. I would hate for it to interfere with their lives, you know, that they'd have to look after me. I chose to look after them. There's a difference, you know, and I do it grudgingly sometimes, you know. They're teenagers, for god's sake. (laughs) So there's times when I feel pretty put upon so I can only imagine if the tables were turned and I was this drooling, dotty, old lady and they had to look after me. I can.... you know, put me in a home. (laughs) That's me, I know, but I wouldn't.... you know, like if I thought that they would do it with any sort of.... or if they could do it.... if they could do it - maybe - but I don't think so.

PS: You don't think that they would or that you wouldn't want them to.

NL10: I don't think I would want them to.

For NL8, it was her children's family responsibilities. For NL10, it was more about her own unease of becoming a burden for her children.

In the account above, NL10 joked about going into a nursing home. Although it was mentioned earlier that ending end up in a nursing home was seen as the end of independence for most, a small number of women felt that the nursing home offered some level of independence from becoming a burden on family members. NL7 was adamant that her children should not be obligated to provide her with care and expressed an expectation that the system would provide care for her and husband should they need it. NL7 did not want to be a burden on her children, favouring nursing home care over living with her children, thus placing a high value on independence.

NL7: Your children deserve their own life, right. So I hope they listen to it when the time comes, right, but I see a lot of problems in the future with health care.

PS: Like what?

NL7: Well, I'm a diabetic now and I'm after having one heart attack and.... you know, but they got me on needles and they got me on pills to stop heart attacks, but that could

happen again tomorrow or, like he says, I'm a prime candidate for strokes. So if I take a stroke and I can't get around, I'm not living with my children. If they can't get a home care worker, put me in a home, right, because your children shouldn't have to do it. I know a lot of people do but I don't believe it should happen...my husband and myself will take care of each other as long as we can; but after that it's either the home or home care - not my children, right - because everybody knows there's going to be problems coming down the road.

In the same way, NZ6 would reluctantly rather live in a nursing home over burdening her brother.

NZ6: ...um what else...I'm concerned that, I do have worry that say I did have some kind of degenerative disease or some problem of the elderly, you know lost mobility, that I might be put in very substandard elderly accommodation, and I don't want to be a burden on my family, cause I've only got my brother and um, you know I'd probably put up with something awful rather than ask him to look after me.

Like NZ6, NL6 has no immediate family to draw support from, so looks to extended family members to provide support.

NL6: I lived with aged parents so I know what it meant to be there for them and I'm not married myself and I don't have immediate family so I have to branch out to my brothers and sisters and, you know, you don't see your nieces or nephews around a whole lot because they have their own families and their own lives. Now if something did happen, I'm sure they would be there for me. I'm hoping I'm right (laughs).

NL6 and NZ6 imply that there is a new understanding developing between extended members of a family or even perhaps community members, that if you help someone out, they will help you out, revealing of a sense of reciprocation.

PS: What role do you think family and friends play in your health care or health generally?

NZ6: Well my brother's a rare and lovely man in that he actually talks about feelings more than most men and I have a very good relationship with him. His partner is a kind woman but I wouldn't want to add to her stress or burden her but I guess if something did happen, if I broke my leg or something, I think she'd look after me and I would certainly do the same

for her, if she was in the same situation, you know I've not even thought of this but now I'm back here, and if she didn't have someone to take care of her I would do that, so I guess there is some sense of a reciprocal support system developing...

NL6 similarly discusses the caring role she provides as a volunteer and hopes this will be reciprocated for herself.

NL6: I work.... or volunteer as well over at the [organisation name deleted to protect privacy of NL6] and I find that the patients over there are very, oh, they're jumping with joy when they see you coming to their room - oh, there's my friend coming. There's my friend coming again. And do you know what, you don't have to do very much. Like Christmas, Easter, bring them over a Christmas card, an Easter card, and they, they hold on to it for dear life and, you know, some of those people don't have any family and they're the ones who need it the most and some of them, you know, do have their families but they still want you to be a part of their lives there, right.

PS: Yeah.

NL6: Yeah. And as I say, I'm hoping that down the road.... that if it should ever come to me, that there will be somebody there when I'm going out.

PS: Yeah.

NL6: That's the way I look at it, you know, because we don't know who.... who really has to look after us before we go out of this world.

Giving one's time in the present may go some way to alleviate the fear that there would be no-one to care for them in the future, as well as foster the good feelings that go with helping out others. However, as can be the way for women, generosity of their time can be abused, as occurred for NZ4.

NZ4: ... I'll tell you this. There's an old man next to me and he's a nice old man, and he's blind and has motor-neuro disease, so it started off with me sort of minding things and doing a few jobs for him, and it got eventually so heavy that I was looking after him, oh, like I used to set my alarm in the middle of the night so I could help him have a pee, cause he had prostate trouble and he was blind so I was conscious of him 24/7. So I wrote to Capital Coast Health, I said you know this gentleman is too much for me looking after him and they wrote back to me and said, I've still got the letter somewhere, that that was too bad and, that's right he went up for an assessment and they sent him again, and they wrote

back to me again and said it was between me and him that they were simply taking his word that he was ok for someone to do his laundry his cooking, his blah blah blah, they'd put ticks by all these boxes. I think I found that out by because he was blind I was reading his mail and this assessment thing came from Capital Coast where it had tick, tick, tick like everything was taken care of, and it said who did that and it was me and I didn't know and I wasn't allowed to know because of the privacy act. So there was I in this situation, responsible for this human being because he said that someone was looking after him and it was me, you know, and oh gee, and when I tried to say to Capital Coast they said, oh that's between you and him, you know, and they weren't going to pick up any responsibility for him, or send out home help or anything like that because I was doing it. And this is how you can get trapped.

Such an issue highlights the negative side of social capital, whereby caring for others implicates women in roles they cannot cope with or do not want to be involved with (Kunitz, 2001; Pearce & Davey Smith, 2003).

Generally, people worry about becoming dependent as it threatens 'values of self-respect and human dignity' and one of the biggest fears of older people is the possible loss of their independence through ill-health (Feldman, 1999; Tannenbaum et al., 2003). This is also true for the women in this study. All the women above have revealed to varying degrees some level of concern over becoming a burden on their immediate or extended family members and some are careful not to be seen to expect too much. What is interesting, however, is that looking after family members is no longer a given in modern society.

3.2.2.1 References to the Past and Other Cultures

With the changing family structure and increasing provision and reliance upon government services, many of the women made references to the past, particularly about the changing role of families and the community in caring for older people.

NZ1: You saw more of your home and family even in those busy times...

NZ3: But life's getting too fast now and no doubt it's going to get faster and people are becoming more me, me, me and less involved with the community spirit... 30 years ago most children went and saw their family on weekends with their parents, 10 years ago they might go and see them every couple of weeks, but these days they, a lot of I suppose, in a lot of families are so busy with their kids they might give the parents a phone call, they're too busy taking the kids to this and that, and, who knows, when I'm in my 60s I might get a video conference call and that might be it...

For NL9, referencing the past centred around a time when not only family but neighbours too rallied around and supported one another. NL9 frequently observed that this didn't happen today, perhaps displaying a sense of sadness over a lost way of life, and about her own future and who will be there to look after her.

PS: How important do you think family is for your health and for your health care. Do you think they play a big part in looking after each other when they're unwell or just...

NL9: Some families do.

PS: Yeah.

NL9: Right. But years ago, your neighbours took a big part too.

PS: Is that right.

NL9:... you know; but neighbours are not like that today. They're not. It's like you don't exist. Now I'm different, if I know my neighbour's sick, I'll call her. I suppose they (inaudible), you know; but they're not the same. People are more on the go. They're not home much and with parents, two people working, you know, so it's a different training and it'll never be the same, you know, never. I don't think it'll ever go back to the old times.

NL11 describes in the past how one could look to their family for care in older age, and in return came certain rights such as inheriting the house.

NL10: (sighs) I don't know. I don't know how.... you know, it's funny - a friend of mine and I were talking about it yesterday, we were going along and it was sort of like who's going to look after us when we get old? It was always traditional that the youngest person in the family looked after the parents until.... you know, and then by doing that, they inherited the house and whatever was in it, you know. That doesn't happen anymore. The families aren't big enough for one thing, you know, and it's such a burden these days for young people just to look after themselves. How are they going to look after an ageing, sick parent. You know, it's like where.... when there was always a daughter at home or when it was a farm and there was a.... you know, so it's changed. The world has changed.

Many of the women from both countries spoke of other cultures that they perceive as treating older family members with much more respect and describe as more willing to care for older family members. In New Zealand this was described by the women observing the way in which the indigenous Maori of New Zealand and Pacific Peoples treated their elders, and the women in both countries made reference to Asian cultures. Such observations are supported by research. In New Zealand, Maori and Pacific Peoples have a much higher proportion of families living with extended family members than New Zealand European families (Statistics New Zealand, 2004c). Similarly, Japanese also have a high proportion of older parents living with their offspring (Jacobzone, 2000). As the role of children caring for adult parents is mediated by the global and specific expectations described earlier, the role of families in caring for parents is also mediated by national cultural contexts (Peek et al., 1998; Jacobzone, 2000).

NZ3: I only know the basics of a few Japanese families, but their culture and philosophy is the old look after the young, you know the grandparents look after the grandchildren, and when the grandchildren are older they'll look after the olds, look after the grandparents, and of course you've always got this two way cycle going. However, even now I see it with these people its changing also and you know now it's a case of these kids are too busy getting their degrees or careers and if the parents don't look after the grandparents well that's too bad. That's I think a philosophy that's gone in New Zealand with Maori and Pacific Islanders. Like 30 years ago when I first got into the rest home scene to see Maori or Polynesian person, I think I saw two Maori gentlemen and one Polynesian but it's their culture to honour to look after their older people whether it be, if the person has no children it would be the niece and nephews...

NL11: Generally speaking, no, we're not.... while our health care needs may be met, we're not just in the scheme of things treated with respect and certainly not what you would be treated with say in China or something, but not in North America. Yeah. No, they're not treated like their years have any value, really - unfortunately.

NZ2: I think the Indian community is the better way because they have parents with the kids, it all comes back to life skills, I suppose it is the parents helping out but it works both ways...

Note in these quotes again a sense of reciprocation among family members, as raised by NZ6 and NL6. These comments are a reflection of the changing societal values around ageing and changing family structure in communities. References to the past and other cultures occur when the women are reflecting on where they fit within the community as an aged woman. Bryant et al. (2001) refer to *normalcy* or a perceived standard for older people. As identified earlier in this chapter, ageing is viewed in a rather negative frame. Roscow (1974, cited in Bryant et. al, 2001) suggests that American society has not yet established social norms and expectations around what it means to age. Roles aren't yet clearly defined and there are no real rites of passage, only negative stereotypes such as older people becoming decrepit and a burden. There is evidence that this is also occurring in New Zealand and Newfoundland. In addition, ageing is seen as a process of decay and decline that requires medical attention, as seen in concern about ending up in a nursing home.

So far the women have described their expectations about ageing, health care, and the role of family. Increasingly, community members are becoming more reliant on government services for care in older age, and this may be in response to the changing family structures in both New Zealand and Newfoundland communities. People are

increasingly living in small family units made up of parents and children only, and there is less contact with, and responsibility for, extended family members, friends and neighbours, as the quotes have described.

There is currently a tension between the balance of family and government responsibility. Participants can be seen to be negotiating the role the government should play versus the role the community should have in caring for its members. Some women pointed out that caring for others is not solely a government or family issue and that others in the community need to take responsibility for community members too.

NZ2: There really needs... I really feel that the government needs to encourage families to help each other to stay healthy and to help one another and if the family's not going to help, then to reach out somewhere else.

NL10: It's not just the government. It's a community issue. It's not just a government issue. The government can look after it if they know what they're supposed to look after; but if my neighbour across the street is over there sick, alone and not.... why don't I know about that?. Why aren't I aware? Isn't it all our.... isn't it our duty to look after each other, you know.

PS: Whose responsibility do you think it is for health care, looking after your health, looking after old people or anything. Do you think it's the government's responsibility or do you think it should be the community's responsibility?

NL11: Yeah. Ideally, it should be a shared thing, you know. It would be nice to have a neighbour drop in and it's nice to have a social worker and someone who can do.... someone come in and do the washing or the cooking, if it's necessary. Yeah, ideally, this circle would be great; but in actual fact, while I think the community is there, I guess sometimes.... well, the health community is there. Sometimes it falls down with the families. You know, everyone is working today, and say friends, well, friends are nice but friends are busy and working. I don't think we can rely too much on family and friends sometimes but, yeah, it should be shared ideally.

Overall, there is a strong emphasis on independence and looking after yourself, and not relying on others to take care of your affairs. But at the same time they see how things were and that there are other countries and cultures where older people are cared for and they are left wondering who will care for them.

3.3 Future Health Care Concerns

Much of the time concerns about the future came through their current experiences with the health care system, sometimes also through stories about people they knew and stories in the news.

Women often shared stories about how much they appreciated the care they received from their GPs in particular. One immigrant women, who now lives in St John's, was quick to point out how lucky and grateful she was for the Canadian health care system, having immigrated from a country where there was little to no health care provision. She subsequently had no concerns for her future health care.

However over the course of the interviews, women's concerns over inadequacies in their health care systems surfaced. A study comparing the health care system perceptions of the public from five countries (New Zealand, Canada, Australia, United Kingdom and United States) revealed that New Zealanders showed the highest level of worry about the future, and this was measured through ability to get affordable care or specialist care, concerns about long-term care and waiting times for non-emergency care. In all the countries, affordability of long term care was of greatest concern (Donelan, Blendon,

Schoen, Davis, Binns, 1999). This has already been evidenced by the concern expressed by women from St John's about paying for home care and nursing home care. Donelan et al. (1999) also revealed that for New Zealanders and Canadians, waiting times for care were also one of the most important problems facing their health care systems. The remainder of this chapter discusses these concerns, in addition to the income issues and treatment differentials that were raised.

3.3.1 Health Care System

Waiting times and waiting lists were a common concern shared by the women. The stories they tell reflect how the inadequacies in the system which cause waiting times impact them on a personal level.

NL10: You know, we're 50. The baby boomers are 50 and we need that service and don't make me wait a year for a mammogram when I'm.... you know, okay, I've already lost one breast, so it's always there in the back of my head that, you know, there's something going to happen; and I want timely.... you know, like I want to be able to make an appointment and go. I want to be able to do this in a timely fashion. I don't want to have to wait a year for my next appointment.

PS: As a low income person what do you want from health care?

NZ3: I think health care should provide you with the basics to feel well again in a time frame that doesn't cause your life to be substandard. Now. I don't think it's meeting that mark at all. If you've got something acute, you have an accident or something like that, the initial care is good, it meets the mark. However the follow up is substandard. If you should need rehabilitation or something like that, I don't see why you should have to wait 3-5 months to have a CT or an MRI or something like that.

NZ7: Well for example, think of all the people that have to go to Australia for radiation treatment because the waiting lists are too long. I mean, that doesn't sound good.

In Newfoundland, waiting times were often seen as the result of staff shortages and some also noted these shortages were caused by health professionals leaving the province, a problem they saw as unique to Newfoundland and Labrador.

PS: So would you change anything else?

NL11: Yes, more money in health care to get more doctors to stay in the province and, of course, see this would solve everything, I think, with more money, more doctors you'd have shorter line ups, better service and I think this would be the main thing that would filter down to all levels and give everyone a break.

In a discussion around waiting times in doctors' surgeries and outpatients, NL3 shared her thoughts:

NL3: I think the same way, like the Janeway Hospital for example, if you bring a child that's sick... from my own experience, I bring one of my kids there. You go in there at 2 o'clock in the day and you can be there until 8 and 9 o'clock that evening or later; and you know, I think that's because of the lack nurses and doctors. They haven't got enough there.

Further, in Newfoundland getting an appointment to see a doctor was a problem for many women.

NL3: Because I mean even if we go visit our family doctor, like NL1 was saying, we still got to wait two or three hours to get in and see a family doctor so I mean you're not going to...

NL1: And that's after waiting a whole week.

NL3: And that's after waiting...that's what I mean – two or three days, right, sometimes a week.

NL4 noted it was a problem that could be alleviated by changing the structure doctors are paid by.

NL4: I want all doctors to be on a salary too.

PS: Yeah. Why is that?

NL4: Then they won't shove people out after two minutes looking for the next MCP⁶ number fix, they wouldn't have the pressure to get someone out of their office and get the new person in and get their MCP number and get \$17.07, or whatever it is they get now.

These accounts support findings by Schoen and Doty (2004) who reported New Zealanders had little trouble accessing physicians within a day, but that many Canadians, particularly those on low incomes, had to wait several days, often five or more. Besides the frequency of waiting times being mentioned, the women's stories also reveal the consequences of waiting for care, mainly being the stress and the worry it causes.

NL6: Waiting is the big problem and it causes more anxiety.

3.3.1.1 Preventive Health Care

Accounts provided by many of the women reveal evidence that healthy lifestyle messages are filtering through communities. Women describe the benefits of healthy lifestyles to ensure good health in the future. The women from Wellington in particular often mentioned the cost savings to the health care system when health promotion is practiced in communities. Yet despite health promotion messages encouraging women to eat well, practice healthy lifestyles and seek preventive health care, long waiting lists

⁶ Medicare Plan

convey other priorities and contradict seeking early care to prevent future health care problems (Meadows et al., 2001). This is evidenced in this research also.

NL10: Even with having had breast cancer, my appointments for mammograms are made a year in advance. Like my next appointment for a mammogram was made in January, and it's for [early February 2003]. So there is a very long, long waiting list for regular, that's pretty scary, for a regular exam...that's not good enough as far as I'm concerned.

The resources to back up prevention messages are not as available as the policy that has created the need and women find themselves advocating on their own behalf for limited resources (Meadows et al., 2001), such as NZ4 found herself doing.

NZ4: My GP... if I ask for a test or anything - oh what about resources... I asked her for a test for calcium after I diagnosed my own B12 deficiency you might say, I asked for a test for calcium, magnesium and potassium, because I had trouble and she said - resources, resources. So I found out how much this test cost, three dollars and the vitamin B12 cost \$9.28, so I have suffered B12 deficiency, and I know I have for many years because it cleared up as soon as I was getting it...and the money that I've spent and taken from the health system, its thousands and thousands, if not hundreds of thousands, as well as my own productivity...

As NZ4 saw it, the cost of a test far outweighed the associated health problems she experienced because of undiagnosed hyperthyroidism. As a result of tighter allocation of health services, which has in part gone some way to contributing to waiting lists, some of the women also spoke about guilt over taking up precious hospital beds or resources. The women also describe rationing their health care, such that they are seen to be careful with precious health care resources and not wasteful, although as NZ3 points out, the services are essential and not a choice or a luxury. In this quote, NZ3 also alludes to a lack of choice that low income people can feel when they access the health system. This will be revisited further through this chapter.

NZ3: But in the future you hear about people being on waiting lists for months for hip replacements, I mean you don't have a hip replacement because you've got nothing else to do, you don't have cancer treatment because you feel like it, it's something that's going to enhance the quality of your life but I think if you're low income you're going to have no bloody choice but to go on a waiting list and in the meantime you've got physical discomfort which causes mental and emotional stress and discomfort.

3.3.1.2 Uncertainty About What Will be Available

There exists uncertainty that health care that will meet the needs of the women will still be available in the future. Participants in this study felt that they could not rely on the system to provide the quality of care they might require. As described earlier, health issues were rarely mentioned. Rather, it was concern about being cared for that was more often raised.

PS: So then you wouldn't want to go to a home?

NL10: Oh hell, no!

PS: Yeah.

NL10: No! I just want to be here for the rest of my days out picking berries, but I mean that's.... that's fine - I know I can't do it, but it would be.... it's a lovely thought.

PS: Yeah.

NL10: You know, so I guess what it is, you just do it as long as you can and, hopefully, there'll be something available for you when you can't.

NZ8: Its hard, you know, you hear about this waiting list and that cut back and you wonder where it's going to stop. I just hope that something will still be there when I need the care. And that they won't make us all pay for it either. Cause those things concern me.

PS: What are your concerns for your future care?

NL4: Oh, I think that the privatisation of our health care is going to make it worse. This situation I'm talking about is going to become worse, not better because I think that the government are giving away the whole health care system...

Concern for the potential consequences of privatisation of health care in Newfoundland was expressed by NL4. NZ3 however saw private health care, which is available in New Zealand, as a way to ensure access to good quality health care, because she could not be certain of the quality of the public health care system in the future.

NZ3: ...But I've had medical insurance for the last 15 years and even though it's been a financial strain at times, I'll keep on that because I feel that having medical insurance will give me a better standard of life when I'm older.

While there was general concern the system would disintegrate in Canada, NL11 was optimistic that something would be available, picking up on the government focus of preparing for an ageing population. Like NL4 above, she also notes that the health care system in Newfoundland may take a partly privatised approach to the provision of health care. However, while hopeful, her closing words suggested uncertainty rather than optimism. This concern about a changing system wasn't as apparent in New Zealand, which is most likely a reflection of the huge changes New Zealanders experienced with their health care system in the early 1990s.

NL11: That's right. That's right. I'm hoping it will be available but there's no way of knowing. It seems to be deteriorating and I think it will still be there but it may not be as good as it is now. It may be partially privatised and there are certain things we'll have to pay for and it may be.... they may have to play around with it to.... you know, it won't be as pure as the initial idea. Tommy Douglas, it was a beautiful.... it was a wonderful idea, but if it's going to become eroded.... but I don't think it'll be destroyed. I think it'll always be here, some kind of service there. Hopefully, with so many older people, that we'll be able to fight for it more and the emphasis... maybe it'll get more off the youth to the mature people. Yeah, I hope it'll still be there. I think so.

This view supports the general feeling among Canadians about future changes in their system they are not comfortable with.

Three of the New Zealand participants raised concern about the allocation of haemodialysis treatment, two mentioning the highly contentious and publicised withdrawal of Rau William's⁷ treatment because of supposed dementia, and diabetes and age. For these women the Rau Williams case was used to describe their unease at the allocation of health care. Threaded through their accounts of this example are concerns about the distribution and allocation of health care, and about autonomy and dignity. The women are perhaps commenting on the potential that this could happen to them in the future.

NZ3: There was that Rau Williams case in Auckland, remember that, he was seen to be in the early stages of dementia, he was a diabetic and his kidneys were failing, they took him off the dialysis machine and it was quite contentious. And he spoke on the radio one morning and I don't think he was sufficiently demented for treatment to have been withheld from him. I've seen someone die of kidney failure and it is the most ghastly death that I've seen, just appalling, absolutely appalling, and I think someone to have to go through that, the mental hell to go through that, knowing that treatment, relief, was being withheld from you, is evil. Especially for a standard treatment like dialysis, I think.

The Rau Williams story undermines health care as a basic value, that you have a right to it, and that you will be cared for when you are unwell no matter what.

NZ4 observes that the system in New Zealand has gone, there is a lack of a caring spirit in New Zealand and again, the negative view of older people in the community is revisited. Yet while people are seen to be a burden on the system, the values on which

⁷ See <http://www.hrc.co.nz/index.php?p=13796&id=234> for a media release on the outcome of this case.

the New Zealand and Canadian systems have been built are supposed to ensure the right to health care of every citizen, as NZ4 argues:

NZ4: You're right though, nobody does care about them. The government don't give a stuff, you're a burden on society, you're a burden on the economy, it's a fact that you are, but you have a right to be. If you've worked all your life,

Such issues are particularly pertinent for the women from New Zealand because of the two-tiered system. This issue will be examined in the next section.

Finally, NZ3 sums up the expectation about the role of the government in her future care, stating that it is a right as a New Zealander to receive public assistance. Yet, she finishes by noting her uncertainty that anything will be there to assist her, a feeling shared by other women from both countries.

PS: When you're older do you hope your children might help...

NZ3: I prefer family but realistically 20 years for about 10 years I worked in a rest home and, it's awful to have to blackmail children to come see their parents and there were the odd ones even on Christmas, and that's just a reality of humanity. I would like my children to look after me when I was older, but if that didn't happen I would expect it my right as a New Zealand citizen to have public assistance, but I don't expect that it's going to be there.

3.3.2 Income Issues

Throughout the women's accounts so far there have been some references to how their income can affect their accessibility to health care. For example women spoke about accessing home care in Newfoundland, and NZ3 talked about retaining private insurance despite the financial strain to ensure herself a good standard of health care in the future.

The remainder of this chapter examines in more detail the financial obstacles low income women experience and their future concerns in this area.

3.3.2.1 Out of Pocket Costs

Finding the funds for out of pocket costs for health care services was of particular concern for many of the women in this research. Research has indicated that low income adults in both New Zealand and Canada experience cost related difficulties accessing health care (Schoen & Doty, 2004). Evidence supporting this was certainly shared by the women in this study. The women often described the financial strain of affording health care in the present and sometimes went on to consider what the future affordability of health care might mean for them. Because of the small number of women in this research it is hard to say whether the Newfoundland or New Zealand women were worse off, and any differences between them mainly reflect differing provision of health care.

Schoen, Blendon, DesRoches and Osborn (2001) report that overall Canadians are protected from costs except for prescription drugs and dental care. Additionally, low income people in both countries were more likely than high income people to go without prescription drugs because of cost. The cost of medication was of particular concern for the St John's women in this study.

NL8: Yeah. I don't know. Like if,.... well, if anybody is on welfare, they got a drug card so they can always get their drugs except the health care got this thing now - oh, this is not covered and that's not covered and something is not covered, you know, and that's making it hard for the poor people to get the necessary drugs that they need and it's costing money and they don't have the money to pay for it and health care won't pay for it. I think that's utterly disgusting, right, really disgusting.

NL6: When you only have a small income coming in, your drugs – once I reach 65, will drugs that I need for my certain health factor...then, will I have enough money to be able to pay for those drugs and will the drugs be able to help me or will they be, you know, something that I would have to drop down the road.

The difference in the degree of concern expressed and frequency with which the cost of drugs mentioned reflects provision of medication in the two countries. The Newfoundland and Labrador government provides prescription drug coverage for residents who, due to the high cost of their medications, may qualify for drug card only benefits (Department of Health and Community Services, 2005). New Zealand on the other hand provides pharmaceutical drugs for a maximum charge, which is either the price of the item or \$15 (which ever is the lesser amount). This amount is reduced if a person visits the doctor frequently, or for those who need a lot of medications. Subsidies also help with the costs once someone has made a set number of visits to their doctor or purchased a set amount of medications (Ministry of Health, 2005b). Therefore in New Zealand lower income people pay less overall for their medication than in Newfoundland.

The potential of the introduction of a fee for essential services in the future was raised by a number of Newfoundland women. They were worried about health care that wouldn't be covered by the public system, causing them to become concerned about finding the money to pay for services not covered by the health care system.

NL1: I'd have to say yes, I have a concern about my future care because if things change with our system and I'm going to be charged a fee to go to hospital if I break a leg or, you know, whatever the case may be, the surgery, minor surgery. If I'm going to be charged for it, unless it's life threatening, I wouldn't be able to afford it right? You know, that would...that would be my concern if Medicare was going to change.

There is already evidence of the strain of out of pocket costs on the women in the research. NL2 opted to change the bandages on her wound site following a knee operation rather than have the public health nurse come over to her house, as she was going to be charged \$50 to do so. Clearly unable to front up with the spare money, NL2 opted to do it herself, risking possible infection or complications.

NL2: I was given that option. Oh yes, yes. They told me if I wanted a public health nurse, I think they calls them, that I could have come in but I'd rather.... I would've rathered to do it myself.... like to try to do it myself ... but if I had to get a nurse to come in to do it, right, they would've charged me.... every time they'd come in, they would've charged me \$50 every time they'd come in.

Sometimes the women in this study had to make a decision, sometimes a sacrifice, whether to fulfil their health needs or fulfil other needs. For example NZ1 chose to buy unsubsidised medication instead of food and NZ3 chose to pay for health insurance instead of food. Similar findings were also reported by Esser-Stuart and Lyons (2002) whose participants were also seen to be making difficult choices between paying for health care and meeting other needs and expenses.

3.3.2.2 Health Care can be Bought

Falling out of concerns over the cost of health care, many women in both countries held the view that wealthier people were treated better in the health system. In the event that people have to find the money to pay for services, women felt that higher income people are in a better position to be able to bear those costs, which goes against universal access for all.

NL1: Something doesn't seem right there, don't it.

NL2: No, it doesn't.

NL1: Right? Something wrong with the health care system there.

NL2: Yes.

NL1: Yeah. And that's not an issue with people if you've got money, they can go okay well, I'll find the money.

Therefore with ability to pay came preferential access to health care. NZ5 also alludes to differing access to health care because of age, suggesting that older people are not treated as well by the health system as younger people. Particularly in New Zealand, there was a view that the health care they received was not up to the standard enjoyed by more wealthy members of their communities, most likely reflecting provision of private health care.

NZ5: I'm darned sure if I was a high profile person I wouldn't have to go through this or if I was a high profile sports person I wouldn't have gone through this regardless of my age.

NL6: ...that could even be your doctor or your lawyer or, you know, in that professional field, I think you would be cared for with the utmost care. But I think people who are low income, they're probably suffering, you know... I think that's a shame, I really do.

3.3.2.3 Private Health Care

Further to this observation was one of the major areas of difference between the accounts of the women in each city: issues surrounding private health care. In New Zealand, citizens are free to take out private health care to access services delivered by private health care providers. However, private health care more often than not is

something only wealthier members of the community can afford. Schoen et al. (2001) state that New Zealanders with low incomes and without private health insurance face financial barriers to receiving care. New Zealanders without private insurance were twice as likely to forgo necessary care because of the cost or difficulty paying medical bills than those with private insurance. Furthermore, New Zealanders with private insurance have shorter waiting times than those without it (Schoen & Doty, 2004). Schoen and Doty also report that higher income New Zealanders were more likely to have private insurance than low income people. Private insurance supplements access to public benefits (double-dipping) and allows faster access to care for higher income people. This means private provision of health care is a major contributing source of inequality in accessing health care in New Zealand.

The accounts provided by the women from Wellington raised similar issues. Mostly the women viewed these inequalities from the perspective of a public system user, however two women actually used private health care to avoid the problems evident in the public system. Overall, the women observe that health care received through the private sector is better quality and faster than the public system, yet to get care through the private system is cost prohibitive. The following quote raises many of these issues.

NZ3: No, I don't feel secure at all and that's why I'd rather not pay food bills and things like that and keep my medical insurance and I speak to that. I had my medical insurance before I had the accident, so my injuries I got from the accident are covered and if these injuries should get worse and if I can't get it through the public system within a reasonable time frame, I'll probably be able to get it through the private. And it's that power of choice that gives you piece of mind whereas if I didn't have the medical insurance and I had a health problem that needed to be dealt with within a short time frame I would just have to be like most Kiwis and wait and be a beggar of the system. Even with medical insurance I would still have to have the money to meet some of the costs, so whereas being low income there is I suppose no advantage having medical insurance for if something major turned up, was it coronary care for heart by-pass or something like that I think its \$40,000 and I think medical insurance will pay 80 percent of that cost.

NZ3 notes that even if one opts for private care, there are still extra costs that occur making private health care even more prohibitive for low income people.

Based on what participants had experienced for themselves or from those they knew, health care through the private system was viewed as superior to care received through the public system. This was also a finding reported in Taylor and Dower's (1997) research. As NZ4 notes, the difference between the care she and her sister, who has private health care, received couldn't be more different. NZ4 also refers again to the ideal of youth, that to be young is to be healthy and free from degeneration.

NZ4: I think it's partly the health care system and it's also partly because I'm a low income nonentity female. If I was Edmund Hilary⁸... and partly because I'm also dependent on the public health system. Because my sister in Auckland, who is much younger than I am and has almost nothing wrong with her, because she's thin, because she's got private health care, is having her cholesterol checked, has had her bone density scanned, she's having all sorts, on account of my mother's severe osteoporosis, all sorts of prophylactic checks and things, and treatments and stuff to keep her in the very best of nick, absolute perfect health, although she's really healthy but she's on, you know, the private health care system...

How very different for NZ4 and other low income New Zealanders who do not have access to such screening and preventive health care measures. It is perhaps no wonder they see the public system as second best, when they see more wealthy community members receiving benefits that only add to their already good health. This

⁸ Sir Edmund Hilary was the first person to climb to the summit of Mount Everest. He is a well-known and well-respected New Zealander.

demonstrates another way that private provision of health care is contributing to the health inequality gap between rich and poor in New Zealand.

NZ4 also mentioned being dependent on the public system. She was not the only New Zealander to raise this, and interestingly not one of the Newfoundland women spoke of this. Such a finding is probably another reflection of the two-tiered system in New Zealand. In the same way that participants value independence in older age, the women feel the same about being independent in other areas too. If you can afford to pay for private health care, you don't have to rely on the government to aid you. This is despite the long standing public health system in New Zealand, which was built for the same reasons and on similar values as the Canadian system.

NZ5: Well you know you can't afford to say up you and go to the private system because you can't afford it, you are so reliant on them doing it properly.

NZ7: I suppose when you're in your early 40s you find it hard to predict what sort of health issues you're having like 20 or 25 years time but I don't think that I would be able to afford, um, private health care, I'm fairly sure I'll be at the mercy of whatever the public system has to offer, yeah, as I say I can about manage a psychiatrist but if there were other things going on, like if something physical crapped out, I'd suspect I'd definitely be at the mercy of what the public system had to offer.

Generally, the accounts in this section reflect an underlying feeling of lack of choice, that the women essentially feel they get what they are given. To have money to pay for health care gives users more options, and means you can afford the best care.

NZ5: You have continuity of care under the private system, you have a choice about who you see under the private system, you have more rights in that sense.

NZ1: I was working at the time, I was able to pay for things, and have the best of doctors, always went to see the specialist, to see an ordinary doctor was considered not always the best, that the specialists were better...

NZ3 sums up her feelings about the provision of private care in New Zealand and the discrepancy of care between the public and private system:

NZ3: I myself have never had any hospital treatment through the private system but a couple of my children have and yes, it was much better. It was a quicker turn around, but better.

PS: How does it make you feel when...

NZ3: Pissed off, why, what do we pay our taxes for, what did my parents and grandparents pay their taxes for.

3.3.3 Being Treated Differently

The two-tiered system in New Zealand, and out of pocket payments for home and nursing home care in Newfoundland, are just two examples raised in this research that reveal inequalities in the provision of health care. Some women also discussed the differing quality of care they received from the public health care system as low income women.

NL3 described her experience with nursing home care in St John's for her elderly uncle. Stressed from the burden of her responsibilities she sought support from the health care system. Instead of receiving relief from care giving and being given support, her uncle was put into a mental hospital and what transpired only added further to her stress. In the end she brought her uncle back home. For NL3, being low income lead to a lack of

choice of services. She saw her income level as the basis for the treatment of her and her uncle. Despite the stress she experienced, allowing her uncle dignity in older age took precedence. NL3's story sums up how she sees low income older people being treated, in stark contrast to the view the women had about how wealthy people were treated which was described earlier.

NL3: I had to.... I couldn't do it. I said, no, you talk about home care and health care and doctors and nurses - I don't think they would be able to help me or to help him.... to put him into an old age home. They preferred to put him into the Waterford Hospital, dope him up on pills, so he didn't know where he was to, didn't understand anything that was going on around him and let him die into the Waterford Hospital. I took him back home with me one year later. Now he's with me again. When it comes to the home care, I don't.... me personally, I think there should be more done when it comes to older people. You know, I don't think they look out for older people like that. But now he's back with me and now if he's living the next 10 years, I'll keep him with me. I know at times it's going to be hard but I'll be.... I'd rather be the one that goes down and see this man in the bed passed away than actually get a phone call that says, well, your uncle passed in here last night or this morning because, you know, with the health care that way.... I think there should be a little more done for elderly people and more.... you know....

And later:

NL1: I don't know but, you know, whatever, but you know, if I had money.... if you had money, would your uncle be treated different?

NL3: You know he would've been treated different...I know the difference when it comes to putting somebody into a mental institution and letting him die or let him live for another 10 years and this is why I took him back with me. You know, it's not right, that wasn't.

Taylor and Dower (1997) describe similar experiences with their participants and state that such interactions leave low income women feeling unsatisfied, powerless and isolated. NL3 clearly felt unsupported by the health system and while it was an emotional 'burden' for her to take her uncle back, it was superior to leaving him in a mental institution where he did not belong. NL4 sums it up:

NL4: And I just.... I feel that if people aren't welcoming to people of different classes in the health care system, those people get the message to go away quite fast.

NL4 goes on to describe her experience with mental health services and professionals when her child was suffering, causing her to become angry and frustrated that she wasn't taken seriously and therefore not receiving the service she deserved.

NL4: I felt that I would not have been sneered at and dismissed if I had been from a wealthy social class. I firmly believe my treatment was based on my low status in society as an unemployed single parent...

In the words of NZ2, when seeking health care she explains:

NZ2: ...health is to be loving and caring, not only of myself but if I ever go to someone like the doctor, I don't want to be treated differently, I would like to be treated well.

Negative experiences have serious consequences as they have the potential to affect these women's health in the future, as such experiences leave women less willing to interact with the health care system, and therefore contribute indirectly to health inequalities.

This chapter has presented the findings from the interviews with low income women in St John's and Wellington. Their stories have provided valuable insights into their concerns and expectations for their future health care. Their accounts will be considered further in the following chapter and the implications for future health care delivery will be discussed.

CHAPTER 4 DISCUSSION

This research was designed to investigate the health care expectations and concerns of two groups of low income women – one residents of St John's, Newfoundland, and the other residents of Wellington, New Zealand. It provides insights into how health care policy can meet the needs of these women and considers the similarities and differences in the accounts of women from these two communities.

In the first part of this chapter, I give consideration to narrative theory as it relates to the women's accounts. This is followed by a discussion of the implications of the findings for future health care of senior, low income women.

4.1 Interpretation Drawing on Principles of Narrative Theory

Narrative theory (Murray 2000; Rappaport, 2000) is used in this section to further explicate the findings from the research. Rappaport and Murray distinguish three types of narratives; personal stories, stories that are unique to individuals; community narratives, stories people with commonalities share; and dominant cultural, or societal level narratives revealing overarching stories about a group of people or a society. These dominant narratives are readily shared by members of a particular culture or community, through stereotypes or shorthand, which invoke well-practiced images and stories.

4.1.1 Personal Narratives

The personal narratives in this research centred around the women's personal experiences with health care. They included stories about long waiting lists, difficulty getting appointments, finding money for out of pocket costs and for costs for an increasingly cost sharing system, the sacrifices that needed to be made to fulfil health care needs, and differential treatment received from the health care system as a low income woman. The women from St John's talked about potential changes in their system that would have a detrimental effect on them. The personal narratives revealed the importance of relationships in the health care encounter and emphasised that health care needs are more than fulfilling just physical health needs. The women also shared personal narratives through stories about the caregiving experiences they, or others they knew, had with their parents and family members and further, what they expect, if anything, to receive from their own children or extended family in terms of caregiving. They also shared stories about their own and other's experiences with home and nursing home care and their expectations for this care when they are older.

4.1.2 Community Narratives

Community narratives are unique to the women's communities, although interestingly, it appeared that the women belonged to more than one community, and drew on several community narratives to tell their stories. Firstly there were community narratives unique to the women from St John's and the women from Wellington. Most obviously, community narratives evident in the accounts of women from St John's described the

lack of home care and pharmaceutical provision. Community narratives specific to the women from Wellington described living with a two-tiered system. The way in which the accounts differed indicate the ways the systems are failing low income women and reveal how the differences in provision by the respective systems impact on the women. In this way, these narratives contribute in part to understanding how health inequalities are perpetuated throughout the health care system. Experiencing difficulties in accessing health care left the women feeling despondent and not wanting to access health care at all.

In another community narrative, women from both cities shared the similar concern that the health care systems they had grown up with would not be available in the future. However, perhaps because the women from Wellington had been exposed to constant change within their system, their outlook was different. It seemed that these women expected greater privatisation of health care and further cut-backs in public services. In comparison, women from St John's spoke only of the possibility of privatisation and expressed concern about changes within and perhaps even loss of their system. The views of the St John's women also reflect public debate about the sustainability and future changes that is frequently heard about their system. Further, the Newfoundland women did not appear to speak as strongly in support of the Canadian system as would have been expected, and as other studies have shown (Murray, 2004). Rather instead, like the women from New Zealand, they expressed concern that there may not be health care available to them in the future. That both groups of low income women spoke more of concern over what might be available may reflect their concern that they might not have the money to pay for needed health care in the future. Further, that Newfoundland women did not speak out in support of the public system as strongly as other studies

have shown may be indicative of the lack of support some felt they received from their health system, as some of the accounts revealed.

Other community narratives came through women identifying with societies and communities with a similar social make-up. Commonalties in the views were apparent for women of both countries when they described the role of families in their future care. As described in the analysis section, women were divided in their views on the role of family in their future care and they drew on different narratives to explain this. Some talked about not wanting to be a burden and of needing to be independent from family, while others described expectations they held for their family members in their future care.

These perspectives lead to an interesting insight into the responsibility the women saw that families, communities and government have in caring for older members of their communities. In making references to the past and other cultures, the women were describing changes within the make up of their communities, and the role the government and their own families might play in their health care. In describing this change, women drew on community narratives that described how in times gone by neighbours cared for and helped each other more. These references to drawing more readily on immediate and extended family reveals a community narrative about a past way of life that is becoming lost in a busy, time-poor society. References to the past also signify a sense of loss over the past way of life and denote perhaps loss of social capital within Newfoundland and New Zealand society. In the same way, the women from both countries made comparisons to the way in which other cultures treated older community members. In this way, the women are perhaps seeing inadequacies in the way their own societies treat older people, and what they can expect from their own families.

In addition, they also offer insight into the changing structure and daily lives of their communities. On the one hand, societies such as those in Canada and New Zealand have been experiencing de-institutionalisation of the elderly, which has perhaps gone some way to foster the strong value of independence, both from the system and from one's own family. On the other hand however, with the trend towards smaller, nuclear and lone-parent households, there are some hints in the narratives about reliance on such institutions. Therefore the onus is on the government to provide services such as home care, nursing home care and health care at no cost to help families deal with caregiving responsibilities they are struggling to provide. On the flipside to this, though, are stretched government resources with health providers working on tight budgets. Instead of employing more health care and home care workers, governments are increasingly relying on informal caregivers to fill the gap. De-institutionalisation has put pressure on community resources to provide this care, with little reward, financial or otherwise.

The tension becomes apparent then between the need for family and communities to care more for their members, and for the government to come forward and provide the care instead on behalf of families and communities. It highlights too a tension between wanting independence, and wanting to rely on family members. Rappaport (2004) argues that a goal in societies such as those in Canada and New Zealand is independence – independence from family and being able to live your own life and do things – but that this goal is not always ideal for individuals and communities.

To some degree these findings suggest the women are not comfortable with the changing role of family in future care and of the diminishing willingness of community members to care for each other due to changes in family household make-up, roles and work patterns. While the women emphasise the importance of independence, references to the past and other cultures imply concern over being alone, perhaps indicating a concern that while your physical needs can be catered for by the health care system, your emotional needs are not if you are on your own and lonely.

That the women's community narratives were diverse highlights that people draw on many narratives to make sense of their lives, and in the case of this research, how these women make sense of their future health care in an evolving society. The differences in their stories have highlighted differences in the experiences of the women from each country with regard to health care. However, their accounts also showed communities are not necessarily geographical, as revealed by the similarities in some of the accounts and views shared by the women from different countries.

4.1.3 Dominant Cultural Narratives

The third narrative described by Rappaport and Murray is dominant cultural narratives. These narratives reveal themselves through 'over learned stories or stereotypes communicated through mass media or other large social and cultural institutions and social networks' (Rappaport, 2000, p. 4). In this research, dominant narratives are picked up by the women and are used to frame current and possible future changes in the system they are not comfortable with. Their concerns reflect a changing system where

financial constraints conflict with high quality, immediate health care. This is seen when the women from Wellington described the Rau Williams story, or when issues such as waiting lists and scant resources are used to frame personal narratives. Stories about waiting lists and limited resources are commonly reported in the media, and are used by the women to frame concerns about overstretched health care funds and resources, and they reflect on the implications this will have for their future care.

Outside of the health care system, dominant narratives were most clearly seen when the women from both countries describe their thoughts on ageing. As illustrated in the analysis, the women often drew on negative stereotypes about ageing and what would happen to them as a result of ageing. Decline, dependence and being a burden were discussed as normal for older age. These issues were used to discuss expectations the women held regarding the role their family or the government would play in their future care. Such findings mirror those of Bryant et al. (2001) who found that women emphasise the importance to health of being able to conform to society's expectations and norms about ageing well, that is, remaining healthy so as not to become a burden on the health care system or their family. Here, concern over decline and becoming a burden refer back to community narratives about remaining independent. For some being independent from family is important. For those from New Zealand, being independent from both family and the health care system may be important.

More generally, it would appear that dialogues over the future sustainability of the New Zealand and Canadian health care systems with respect to the impact of increased costs to the health systems due to new technologies and medicines, the difficulty of providing timely access to health care, and the impact of an ageing population on health care

systems among others have permeated into the public consciousness. The women seemed genuinely concerned about how such issues would impact on them personally in the future.

The above description of the findings from this research reveals that the boundaries between the three types of narratives are not clear cut. Overlaps and relationships exist between each, blurring boundaries. Overall, the key finding to emerge from the research was concern over who or what would be available to care for the women in the future. Concern regarding care, in particular absence of care, centred around the government via the health system, and through their family and wider community. In the absence of immediate family, or for others the choice to remain independent, care provided by the government (including overall health care, home care, and nursing home care) was seen as essential for the women's future health care. Yet the women harbour much concern and worry that nothing will be available to ensure their needs are going to be met in the future, due to the absence of adequate provision of home and nursing home care in Newfoundland, a perception of a disintegrating system in Canada, the user-pays, two-tiered system in New Zealand, and for women from both countries, increasing out of pocket costs. Further, the changing structure of communities means care by families is not a given anymore. Women are coming to grips with changing expectations around the role of families. The care provided by the government is expected to replace that gap. However, underlying the women's accounts is uncertainty that their governments will be able to provide care either. Worse for low income women are the implications of increasingly cost-sharing systems. They worry about who will care for them if they are not able to rely on family and have to pay for care. It is seen by the women who

participated in this research as easier for those who are more well off to get better treatment and to cover the extra costs for health care as they arise.

Framing the accounts in terms of Murray's and Rappaport's narrative typology has revealed the issues that are important to the women. Given these, what implications does this have for the future health care of these women? And how can the respective health care systems better meet their needs with their concerns and expectations in mind? The second part of this chapter presents possible solutions to the concerns and expectations expressed by the women interviewed. Firstly, overarching strategies for health care and the community are briefly discussed, followed by a discussion of specific areas the health care system could focus on to address the needs of the women in this research.

4.2 Implications for Future Health Care

4.2.1 Overarching Strategies

There is consensus in the literature reviewed for this research that economic, social and political structural causes of health inequalities should be tackled before individual interventions are used (Graham, 2001; Green, 2001; Pearce & Davey Smith, 2003; Reutter et al., 2001; Wilkinson, 1996). However, the health problems caused by health inequalities that reveal themselves in the form of illness are currently dealt with once they have already manifested in individuals when they appear for treatment via the health care system (Denny, 2002; Lott & Bullock, 2001; Pearce & Davey Smith, 2003;

Wilkinson, 1996). Ideally, policies that give low income people more money and facilitate better opportunities to access good employment and education will reduce health inequalities. Additionally, the recognition by governments of the problems that financially unequal societies cause, and subsequent redistribution of wealth, would help to reduce both financial and health inequalities.

Besides making overarching structural changes, there may be some value in strengthening communities by building social capital. The present study points to a loss of social capital, as mentioned earlier in this chapter, with women feeling less able to rely on those around them for care. Efforts to increase social capital relevant for the women in this research could include fostering a sense of duty to look out for all members of communities. However, one of the issues identified with building social capital within communities is that many communities are overburdened already. Many families hardly have time to dedicate to their own members, let alone to extended families, neighbours and friends.

In any case, building social capital could be achieved via a long term social marketing campaign. Social marketing campaigns employ various strategies to convey public health messages for the achievement of socially desirable ends (Donovan & Henley, 2003). The strategies are conveyed using, among other things, television, print, and radio advertising, public relations work, advocacy, and at the ground level, a workforce of community workers ensuring that communities have the resources to be able to implement the messages they choose to take on board. Having the emotional security of knowing that other people in the community are looking out for you would go some way to reducing concern about being left alone without care. Moreover, policies that allow time

from work to care for ailing parents and family members also contribute to building social capital by freeing up time for caregivers and relieving stress levels associated with caregiving, thereby reducing illness generally.

It is fair to say that dealing with health inequalities is part of the health strategy in New Zealand, however, there is no overtly stated commitment to reducing inequalities in the Canadian Health Accord. In both countries, there is evidence that the governments are considering building social capital to strengthen communities and improve health, although this policy shift is in its early stages. Any action taken to reduce health inequalities and to build social capital will have positive effects for low income women so long as such actions are targeted at their specific needs.

4.2.2 Health System Specific Strategies

While tackling structural causes of health inequalities and strengthening communities are ideal goals, such changes if they happen will occur over the longer term. Many of the health problems that result from being low income require immediate intervention by the health care system. Therefore, it is important that health care is delivered to low income women that will meet their needs when they access health care both now and in the future.

Findings in this research certainly support the existing evidence that health care systems in themselves contribute to health inequalities (Leon & Walt, 2001; Mackintosh, 2001). In New Zealand the two-tiered system favours higher income people who do not need

health gains as much as lower income people do. Unequal access to home and nursing home care, and inadequate provision of medicines in Newfoundland disadvantage low income women. In both countries, out of pocket costs mean women sometimes have to choose between meeting health care needs and meeting other needs. The remainder of this section discusses these issues in more detail.

New Zealand needs to seriously examine how its two-tiered system is contributing to health inequalities. While the public system is not making people unhealthy, unfortunately the private system is making higher income people healthier, thereby driving in part the widening health gap between the classes. Higher income people are receiving more timely access to health care, and have better access to care because their ability to pay. Such issues therefore go against issues of fairness and universal access for all (Ministry of Health, 2004a). The two-tiered system in New Zealand encourages the better off members of New Zealand society to segregate themselves institutionally by leaving the public system only for low income people (Mackintosh, 2001).

While the women from St John's harboured concern over changes in their system, and not being able to afford services in the future, they were generally happier with their system compared to the women from Wellington, many of whom felt their public system was second rate to the private system. During their accounts, some women from St John's expressed concern about the possibility of privatisation of their health care system in the future. Interestingly, the figures presented in the introduction revealed that the Canadian private contribution accounted for a higher percentage of health funding than New Zealand and the Newfoundland and Labrador health system has a similar

private contribution to New Zealand. Such concerns expressed by women from St John's are therefore no surprise. However, it is the way in which the women from the different countries talk about their systems that reveals the detrimental effect private provision of health care delivered via a two-tiered system has on low income women, such as seen in New Zealand. The differences in how the women talk about private contributions and health care reflect the problems two-tiered systems cause, with higher income New Zealanders advantaged with extra services those on low incomes are unable to access. It becomes about the have and have nots of health care.

Given the findings from this study, it would seem disadvantageous for low income women if the Canadian health system, and the health care system in Newfoundland and Labrador, to allow a two-tiered health system in the future, as fair access to health care regardless of ability to pay cannot be guaranteed. For the New Zealand system, some suggestions to improve health outcomes and fairness between the private and public system have been put forward. They include: subsidising eligible low income patients to receive their care through the private system when necessary; eliminating private insurance holder's ability to claim back user charges for physician visits and pharmaceuticals; charging private insurers for costs when their insurance holder is referred into the public system; and implementing measures to preclude patients from queue jumping by moving between the private and public systems at whim (Ministry of Health, 2004a). Additionally, regulations, such as those employed in Australia, address such issues by not allowing private insurers to discriminate on the basis of age, or existing illness or disability (Ministry of Health, 2004a). Particularly for New Zealand, Graham (2001) argues to foster middle-class duty to others and reduce reliance on

privilege. Such a view is also supported by Leon and Walt (2001) who argue that institutional segregation by leaving public services for the poor should be discouraged.

The lack of adequate pharmaceutical provision in Newfoundland and Labrador is also an issue. Being unable to afford medicines or concerns about the possibility of having to go without them in the future was particularly concerning for women in Newfoundland. These interviews were conducted prior to the First Ministers Accord on Health Care Renewal, therefore it is hoped that changes will occur in the Canadian system and subsequently the Newfoundland and Labrador system, to provide subsidised medicines to low income, senior women to diminish their concerns about having to go without medications because of lack of income.

The Newfoundland and Labrador government also need to ensure home care is available to those who need it without financial burden, allowing women to remain living independently at home. It is expected that some improvement would also be occur in home care provision in Newfoundland and Labrador from outcomes of the Health Accord. The Newfoundland and Labrador government need to ensure the rights of low income women are protected as would be by those in full-time and/or higher paying jobs, such that they can take time out of their work to look after family members, as also set out the Health Accord.

Both countries need to ensure good quality nursing home care is provided, subject to national standards, and ensure that low income women have access to the same facilities as higher income women. Public, and for that matter private nursing homes,

should be places where people want to be to enjoy their senior years if their circumstances deem it necessary to have nursing home care.

Generally, necessary health needs, including health care for health problems, medications, screening and after surgery care will be provided in a timely way, and heavily subsidised or free, so low income women are not forced into making a decision between meeting health needs or meeting other personal needs. Policies should also ensure that low income, older women's rights are protected in the health care setting, without interference from relatives.

In considering both overall strategies and health care specific strategies, the best solution to ensuring the health care needs of low income women will be met in their senior years, and to address their concerns that there would not be anything or anyone to care for them, would ideally include a combination of both. It is also important that the governments come forward and provide health care and not expect the community to pick up the deficits for care left by funding gaps. Families and caregivers need support, both financially and emotionally. Therefore, as well as government directed strategies to ensure the health needs of low income women will be met, communities in general also need to take responsibility for the well being of other members of their communities.

4.3 Context of Research

In this final section, the context in which the research was conducted is considered. Many authors highlight the importance of 'place' and context when researching health

inequalities (Blaxter, 1997; Chamberlain, 1997; Murray, 2000; Popay et.al., 1998; Roberts, 2005; Sandlewski, 2001). Murray (2000) in particular emphasises the role of the researcher in influencing and shaping the stories told by participants. He has described this as the positional level of narrative accounts. For this research, the positional context for the Canadian interviews was myself as a younger student from a foreign country asking women about their future health care. For the New Zealanders, they were talking to someone from their own country, but still a young researcher, who does not know what it is to be nearing 65. From what can be gathered, this did not affect the outcomes of the interviews as it appeared that the women openly shared their thoughts and appreciated the opportunity to share their stories. Further, the interviews often had a conversational tone to them. In fact, particularly for the Canadian interviews, the women took the position of 'expert' in telling me what I needed to know about the Canadian health system or their experiences with health care. In this way, the women ensured that I had the correct information from which to be able to tell their stories. Therefore, the positional level of narratives can go both ways in that it is possible that the interviewees are also able to affect how the researcher behaves in the interview situation. Such a position can lead the researcher to ensure that they come across as worthy and competent to receive the participant's accounts, as I felt when I was conducting this research.

The findings need to be considered within the societal context within which the research was undertaken. Details of the changes underway in Newfoundland and Labrador and in New Zealand society were described in the introduction. The women's accounts shared in this research are embedded within these changing societies. Women from Wellington did not talk about future changes in their health system with the same anxiety as the

women from St John's spoke of change. This may be due to a greater degree of security with their economy and with their health system or may perhaps even signify complacency over having lived through so many changes to health care and expecting more in the future. A return to a more community-based system delivered via PHOs does see New Zealand returning to a model of which residents are generally supportive. It will be some time before the positive benefits of this change are seen and this research was conducted in the early stages of the new system.

In Newfoundland and Labrador, the collapse of the fisheries has had a profound effect on the lives of its residents. This event, combined with declining federal government support for social systems, meant the women lived in a less secure environment. This was apparent when they expressed concern about the possible changes that could be made to their long-standing health care system. Since the interviews were conducted, Romanow released his report and the federal government has invested more financial resources both in health care and in Newfoundland and Labrador. For now, the Canadian system has been strengthened and spared major reform and optimistically these changes should improve access for those on low incomes in several areas.

The many similarities between the views of the two groups of women from different countries suggest that the findings could apply to other low income women in other urban areas in both countries. The accounts of these women indicate that in both countries being on low income creates challenges in accessing quality health care. Governments in both countries need to be vigilant in ensuring that low income women do not miss out on health care because of inability to pay.

Finally it is important to note that the women came from cities with relatively easy access to health services. Women living in isolated areas of Newfoundland and Labrador or New Zealand may express different views on health care. Further, their views are generational and it is uncertain whether women who are younger or older than those interviewed would have the same needs. Additionally, care should be taken with the results as the research was conducted with a small group of women. Research on larger groups of low income women would need to be conducted to confirm these findings. Overall however, it is important that policy is reviewed and refreshed to reflect the needs of those for who the policies are intended.

4.4 Conclusion

This research set out to examine the future health care expectations and concerns of a group of low income women in St John's, Newfoundland and Wellington, New Zealand, to identify the future health care issues that are important for these women, and to consider how health policy may shape and align health care services to meet the future needs of low income, senior women.

The women interviewed in this research are part of the cohort of people who will cause a bulge of seniors from 2015 onwards. Because health funding will be tight, as it is today, health dollars should be spent where the most benefit will be gained. This research has identified areas where such funding should be targeted, namely ensuring low income, senior women have timely access to health care that is not financially compromising. The women's accounts highlighted lack of provision of adequate pharmaceutical and home

care coverage in Newfoundland, and the presence of a two-tiered system in New Zealand, as key areas that could be refined by each system to ensure low income New Zealand and Newfoundland women could benefit more from their systems.

The findings of this research supports existing evidence that health care systems within themselves can contribute to health inequalities by restricting access due to cost, provision, and unequal treatment by health professionals. Governments need to ensure low income women will receive the same treatment in the health care system, whether it is private or public, as other citizens in New Zealand or Newfoundland and Labrador. Further, because those on low incomes have poorer health outcomes, good access to health care is even more important. Strategies to reduce low income need to be implemented alongside strategies to ensure that current health problems are treated by the health care system in a timely and low cost way and these were discussed in this chapter. The scope for making wider structural changes to the social, political and economic environment in which the women live and building social capital was also presented.

Finally, just stating the value that health care will be provided for all, regardless of ability to pay, does not necessarily mean that this is the case in reality. To be true to the values on which the New Zealand and Canadian health systems were built, governments need to continually ensure low income senior women will have unimpeded access to quality health care. In universal systems such as those provided in New Zealand and Newfoundland and Labrador, Canada, methods such as targeting and population based funding need to continue to be employed to ensure that those most in need receive health care. There is uncertainty about the future sustainability of health care in both

countries, however governments need to ensure that the health care systems will take care of the needs of low income women in the future no matter what their situation.

REFERENCES

- Ajwani, S., Blakely, T., Robson, B., Tobias, M., & Bonne, M. (2003). *Decades of disparity: Ethnic mortality trends in New Zealand 1980-1999*. Wellington: Ministry of Health and University of Otago. [On-line]. Retrieved April 19, 2005 from the World Wide Web: <http://www.moh.govt.nz>.
- Alleyne, G.A., Casas, J.A., & Castillo-Salgado, C. (2000). Equality, equity: Why bother? *Bulletin of the World Health Organisation*, 78(1), 76-77.
- Armstrong, P. (2002). Health care privatisation: Women are paying the price. *Network*, Spring/Summer, 2002, 7-8.
- Aronson, J. (1994). A pragmatic view of thematic analysis. *The Qualitative Report*, 2(1).
- Ashton, T., Mays, N., & Devlin, N. (2005). Continuity through change: The rhetoric and reality of health reform in New Zealand. *Social Science & Medicine*, 61, 253-262.
- Blaxter, M. (1997). Whose fault is it? People's own conceptions of the reasons for health inequalities. *Social Science & Medicine*, 44(6), 747-756.
- Blendon, R., Schoen, C., DesRoches, C., Osborn, R., & Downey, D. (2002a). *Canadian adults' health care system views and experiences*. Pub. No. 552. [On-line]. Retrieved October 17, 2004 from the World Wide Web: <http://www.cmwf.org>.

Blendon, R.J., Schoen, C., DesRoches, C.M., Osborn, R., Scoles, K.L., & Zapert, K. (2002b). Inequities in Health Care: A Five-Country Survey. *Health Affairs* 21(May), 182–91.

Boychuk, G.W. (2002). *The changing political and economic environment of health care in Canada*. Ottawa; Commission on the Future of Health Care in Canada. [On-line]. Retrieved August 1, 2005 from the World Wide Web: <http://www.healthcarecommission.ca>.

Bryant, L.L., Corbett, K.K., & Kutner, J.S. (2001). In their own words: A model of healthy aging. *Social Science & Medicine*, 53(7), 927-941.

Canadian Institute for Health Information [CIHI]. (2002). *Health Care in Canada*. Ottawa: CIHI. [On-line]. Retrieved October 12, 2002 from the World Wide Web: <http://www.cihi.ca>.

Canadian Institute for Health Information [CIHI]. (2004). *National Health Expenditure Trends 1975 – 2004*. Ottawa: CIHI. [On-line]. Retrieved April 29, 2005 from the World Wide Web: <http://www.cihi.ca>.

Canadian Research Institute for the Advancement of Women [CRIAW]. (2002). *Women and poverty*. Ottawa: CRIAW

- Capital & Coast District Health Board. (2004). *Care coordination centre: Service specifications*. [On-line]. Retrieved April 29, 2005 from the World Wide Web: http://www.ccdhb.org.NZ/publicconsult/HCPS/Care_Coordination_25.pdf.
- Chamberlain, K. (1997). Socio-economic health differentials: From structure to experience. *Journal of Health Psychology*, 2(3), 399-411.
- Chamberlain, K. (1999). Using grounded theory in health psychology: Practices, premises and potential. In M. Murray & K. Chamberlain (Eds.), *Qualitative Health Psychology: Theories & Methods* (pp. 183-201). London: Sage.
- Coory, M.D. (2004). Ageing and healthcare costs in Australia: A case of policy-based evidence? *Medical Journal of Australia*, 180, 581-583.
- Crampton, P. (2002). Cutting up the health funding cake – targeting vs universalism. *PHA News*, V(4), 1-3. [On-line]. Retrieved March 4, 2005 from the World Wide Web: <http://www.pha.org.nz>.
- Dahlgren, G. & Whitehead, M. (1991). *Policies and strategies to promote equity in health*. Copenhagen: World Health Organization Regional Office for Europe.
- Davey Smith, G., Gunnell, D., & Ben-Shlomo, Y. (2001). Life-course approaches to socio-economic differentials in cause-specific adult mortality. In D. Leon & G. Walt (Eds.), *Poverty, inequality and health: An international perspective* (pp. 88-124). Oxford: Oxford University Press.

Davis, D., & Gerrard, S. (2000). Introduction: Gender and resource crisis in the North Atlantic fisheries. *Women's Studies International Forum*, 23(3), 279-286.

Davis, P., & Ashton, T. (2001). *Health and public policy in New Zealand*. Auckland: Oxford University Press.

Denny, K. (2002) *Discomforting regularities: Fathoming the resilience of health inequalities*. Unpublished manuscript, University of Toronto at Toronto.

Department of Health and Community Services. (2002). *Healthier together: A strategic health plan for Newfoundland and Labrador*. St John's: Department of Health and Community Services. [On-line]. Retrieved March 5, 2002 from the World Wide Web: <http://www.gov.nf.ca/health/strategichealthplan>.

Department of Health and Community Services. (2004). *HealthScope 2004: Reporting to Newfoundlanders and Labradoreans on comparable health and health system indicators*. St John's: Department of Health and Community Services. [On-line]. Retrieved March 26, 2005 from the World Wide Web: <http://www.health.gov.nl.ca/health/>.

Department of Health and Community Services. (2005). *Overview of the Newfoundland and Labrador prescription drug program*. [On-line]. Retrieved April 26, 2005 from the World Wide Web: <http://www.health.gov.nl.ca/health/nlpdp/overview.htm>.

Devlin, N., Maynard, A., & Mays, N. (2001). New Zealand's new health sector reforms: Back to the future? *British Journal of Medicine*, 322, 1171-1174.

Donelan, K., Blendon, R.J., Schoen, C., Davis, K., & Binns, K. (1999). The cost of health system change: Public discontent in five nations. *Health Affairs*, 18(3), 206-216.

Donelan, K., Blendon, R.J., Schoen, C., Binns, K., Osborn, R., & Davis, K. (2000). The elderly in five nations: The importance of universal coverage. *Health Affairs*, 19(3), 226-235.

Donovan, R.J., & Henley, N. (2003). *Social marketing: Principles & practice*. Melbourne: IP Communications.

Esser-Stuart, J.E., & Lyons, M. (2002). Barriers and influences in seeking care among lower income minority women. *Social Work in Health Care*, 35(3), 85-99.

Federal, Provincial and Territorial Advisory Committee on Population Health [FPTACPH]. (1999). *Toward a healthy future: Second report on the health of Canadians*. Ottawa: FPTACPH.

Feldman, S. (1999). Please don't call me 'dear': Older women's narratives of health care. *Nursing inquiry*, 6, 269-276.

Flick, U. (2005). *An introduction to qualitative research*. London: Sage.

- Gair, S. (2002). In the thick of it: A reflective tale from an Australian social worker/qualitative researcher. *Qualitative Health Research*, 12(1), 130-139.
- Gauld, R. (2001). *Revolving doors: New Zealand's health reforms*. Wellington: Victoria University.
- Graham, H. (1984). *Women, health and the family*. Great Britain: Wheatsheaf.
- Graham, H. (2001). *From science to policy: Options for reducing health inequalities*. In D. Leon & G. Walt (Eds.), *Poverty, inequality and health: An international perspective* (pp. 294-311). Oxford: Oxford University Press.
- Green, K. (2001). Empowerment in the context of poverty: Low-income mothers in Saskatoon. *Centres of Excellence for Women's Health Research Bulletin*, 2(2), 17-18.
- Gupta, G.R. (2000). Round table discussion: Equity and gender. *Bulletin of the World Health Organisation*, 78(1), 81-82.
- Gwatkin, D.R. (2000). Health inequalities and the health of the poor: What do we know? What can we do? *Bulletin of the World Health Organisation*, 78(1), 3-18.
- Hall, J., & Scoobie, G. (2005). *Capital shallowness: A problem for New Zealand?* [Online]. Retrieved 1 August, 2005 from the World Wide Web: <http://treasury.govt.nz>

Hamilton, L.C., Haedrich, R.L., Duncan, C.M. (2004). Above and below water: Social/ecological transformation in Northwest Newfoundland. *Population and Environment*, 25(3), 195-215.

Health Canada (1997). *Canada Health Action: Building on the Legacy*. Ottawa, ON: Health Canada.

Health Canada. (2001). *Inuit health initiatives with the Government of Canada*. [On-line]. Retrieved April 19, 2005 from the World Wide Web: <http://www.hc-sc.gc.ca/english/media/releases/2000/>.

Health Canada. (2004a). *Commitments to Aboriginal health*. [On-line]. Retrieved March 26, 2005 from the World Wide Web: <http://www.hc-sc.gc.ca/english/hca2003/>.

Health Canada. (2004b). *The 2003 Accord on Health Care Renewal: A progress report*. [On-line]. Retrieved March 26, 2005 from the World Wide Web: <http://www.hc-sc.gc.ca/english/hca2003/>.

Health Canada. (2004c). *A 10-year plan to strengthen health care*. [On-line]. Retrieved March 26, 2005 from the World Wide Web: <http://www.hc-sc.gc.ca/english/hca2003/>.

Health Canada. (2004d). *Overview of the health care system*. [On-line]. Retrieved March 26, 2005 from the World Wide Web: <http://www.hc-sc.gc.ca/english/hca2003/>.

Health Canada. (2004e). *The Canada Health Act*. [On-line]. Retrieved March 26, 2005 from the World Wide Web: <http://www.hc-sc.gc.ca/english/hca2003/>.

Health Reforms 2001 Research Team. (2003). *Interim Report on Health Reforms 2001 Research project*. Wellington: Health Services Research Centre. [On-line]. Retrieved August 1, 2005 from the World Wide Web: <http://www.vuw.ac.nz/hsrc/reports/downloads>.

Iglehart, J.K. (2000). Revisiting the Canadian health care system. *New England Journal of Medicine*, 342(26), 2007-2012.

Jacobzone, S. (2000). Coping with aging: International challenges. *Health Affairs*, May/June, 213-225.

Kriebler, T.A. (2000). New Zealand. *Journal of Health Politics, Policy and Law*, 25(5), 925-930.

Kunitz, S.J. (2001). Accounts of social capital: The mixed health effects of personal communities and voluntary groups. In D.A. Leon & G. Walt (Eds.), *Poverty, inequality and health: An international perspective* (pp. 159-174). Oxford: Oxford University Press.

Leon, D.A., & Walt, G. (Eds.). (2001). *Poverty, inequality, and health: An international perspective* (pp. 1-16). Oxford: Oxford University Press.

Lott, B., & Bullock, H. (2001). Who are the poor? *Journal of Social Issues*, 57(2), 189-206.

Lowry, J.A. (2002). The evidence is in...its time to act on homecare. *Network*, Spring/Summer 2002, 4-6.

National Advisory Council on Aging. (2002). *Modernizing Medicare for an aging population: Aging and costs*. [On-line]. Retrieved April 19, 2005 from the World Wide Web: http://www.naca-ccnta.ca/expression/14-1/exp14-1_3_e.htm.

MacDonald, M. (1998). The impact of a restructured Canadian welfare state on Atlantic Canada. *Social Policy & Administration*, 32(4), 389-400.

Mackintosh, M. (2001). Do health care systems contribute to health inequalities? In D.A. Leon & G. Walt (Eds.), *Poverty, inequality, and health: An international perspective* (pp. 175-193). Oxford: Oxford University Press.

McClintock, B. (1998). Whatever happened to New Zealand? The Great Capitalist Restoration reconsidered. *Journal of Economic Issues*, XXXII(2), 497-503.

Maharey, S. (2005). *Strong employment growth returns NZ to number one in the world*. [On-line]. Retrieved 12 August, 2005 from the World Wide Web: <http://www.beehive.govt.nz>.

Marmot, M. (2000). Social determinants of health: From observation to policy. *Medical Journal of Australia*, 172, 379-382.

Meadows, L.M., Thurston, W.E., & Berenson, C.A. (2001). Health promotion and preventive measures: Interpreting messages at midlife. *Qualitative Health Research*, 11(4), 450-463.

Ministry of Health (2000). *The New Zealand Health Strategy*. Wellington: Ministry of Health. [On-line]. Retrieved April 27, 2003 from the World Wide Web: <http://www.moh.govt.nz>.

Ministry of Health. (2001). *Health Facts July 2001*. [On-line]. Retrieved April 27, 2003 from the World Wide Web: <http://www.moh.govt.nz>.

Ministry of Health. (2002a). *Reducing inequalities in health*. Wellington: Ministry of Health.

Ministry of Health. (2002b). *Health Expenditure Trends in New Zealand 1990 – 2001*. Wellington: Ministry of Health. [On-line]. Retrieved August 27, 2003 from the World Wide Web: <http://www.moh.govt.nz>.

Ministry of Health. (2003). *New Zealand Health and Disability Sector Overview*. Wellington: Ministry of Health. [On-line]. Retrieved August 27, 2003 from the World Wide Web: <http://moh.govt.nz>.

Ministry of Health. (2004a). *Future Funding of Health and Disability Services in New Zealand*. [On-line]. Retrieved January 27, 2005 from the World Wide Web: <http://www.moh.govt.nz>.

Ministry of Health. (2004b). *Health expenditure trends in New Zealand 1999-2002*. Wellington: Ministry of Health. [On-line]. Retrieved March 26, 2005 from the World Wide Web: <http://www.moh.govt.nz>.

Ministry of Health. (2004c). *Health report: Southern Cross publication on rebate for private health insurance*. [On-line]. Retrieved March 26, 2005 from the World Wide Web: <http://www.moh.govt.nz>.

Ministry of Health. (2005a). *Primary Health Care Strategy*. [On-line]. Retrieved February 23, 2005 from the World Wide Web: <http://www.moh.govt.nz/primaryhealthcare>.

Ministry of Health. (2005b). *Guide to eligibility for publicly funded health and disability services in New Zealand*. [On-line]. Retrieved April 26, 2005 from the World Wide Web: <http://www.moh.govt.nz/moh.nsf/>.

Ministry of Housing. (2002). *Ministerial Briefings 2002*. [On-line]. Retrieved August 5, 2005 from the World Wide Web: <http://www.beehive.govt.nz>.

Moen, P., & Forest, K.B. (1995). Family policies for an aging society: Moving to the twenty-first century. *The Gerontologist*, 35(6), 825-830.

- Mulder, D.S. (2001). Current health care crisis: A Canadian perspective. *Archives of Surgery*, 136, 169-171.
- Murray, M. (2000). Levels of narrative analysis in health psychology. *Journal of Health Psychology*, 5(3), 337-347.
- Murray, M. (2004). *Canadian babyboomers' beliefs about health, illness, aging and healthcare*. Paper presented to the Community of Applied Psychologists, Auckland, New Zealand, December 2004.
- Murray, M., Pullman, D. & Heath Rodgers, T. (2003). Social representations of health and illness among baby-boomers in Eastern Canada. *Journal of Health Psychology*, 8(5), 485-499.
- National Advisory Council on Aging. (2002). *Modernising Medicare for an aging population*. [On-line]. Retrieved April 19, 2005 from the World Wide Web: <http://www.naca-ccnta.ca>.
- Naylor, C.D. (1999). Health care in Canada: Incrementalism under fiscal duress. *Health Affairs*, May/June, 9-26.
- Oermann, M. (1999). Consumers' descriptions of quality health care. *Journal of Nursing Care Quality*, 14(1), 47-55.

- OECD Health. (2004). *Total expenditure on health % GDP*. [On-line]. Retrieved May 17, 2005 from the World Wide Web: <http://www.irdes.fr/ecosante/OECD/411010.html>.
- Pearce, N., & Davey Smith, G. (2003). Is social capital the key to inequalities in health? *American Journal of Public Health, 93*(1), 122-129.
- Pederson, A. (2001). What makes us healthy, what makes us sick? *Centres of Excellence for Women's Health Research Bulletin, 2*(2), 1-3.
- Peek, M.K., Coward, R.T., Peek, C.W., & Lee, G.R. (1998). Are expectations for care related to the receipt of care? An analysis of parent care among disabled elders. *Journal of Gerontology, 53B*(3), S127-S136.
- Pinquart, M., & Sorensen, S. (2002). Factors that promote and prevent preparation for future care needs: Perceptions of older Canadian, German, and U.S. women. *Health Care for Women International, 23*, 729-741.
- Popay, J., & Williams, G. (1996). Public health research and lay knowledge. *Social Science & Medicine, 42*(5), 759-768.
- Popay, J., Williams, G., Thomas, C., & Gatrell, A. (1998). Theorising inequalities in health: The place of lay knowledge. In Bartley, M., Blane, D. & Davey Smith, G. (Eds.), *The Sociology of Health Inequalities* (pp. 59-83). Oxford: Blackwell Publishers.

Public Health Agency of Canada. (2002). *Aging and seniors: Canada's seniors at a glance*. [On-line]. Retrieved April 19, 2005 from the World Wide Web: http://www.phac-aspc.gc.ca/seniors-aines/pubs/seniors_at_a_glance/.

Raphael, D. (2001). *Inequality is Bad For Our Hearts: Why Low Income and Social Exclusion are Major Causes of Heart Disease in Canada*. Toronto: North York Heart Health Network.

Rappaport, J. (2000). Community narratives: Tales of terror and joy. *American Journal of Community Psychology*, 28(1), 1-24.

Rappaport, J. (2004). *Keynote address*. 9th Biennial Australia-Aotearoa (New Zealand) Community Psychology Conference, 5-7 July 2004, Tauranga, New Zealand.

Reutter, L., Neufeld, A., & Harrison, M.J. (2000). A review of the research on the health of low income women. *Canadian Journal of Nursing Research*, 32(1), 75-97.

Roberts, J. (2005). Recreating experiences: Improving validity of data. *Evaluation Journal of Australia*, 4(1&2), 44-51.

Romanow, R. (2002). *Shaping the future of health care: Interim report*. Ottawa: Health Canada. [On-line]. Retrieved March 4, 2003 from the World Wide Web: <http://www.healthcarecommission.ca>.

Sandelowski, M. (2002) Reembodying qualitative inquiry. *Qualitative Health Research*, 12(1), 104-115.

Sanmartin, C., Ng, E., Blackwell, D., Gentleman, J., Martinez, M., & Simile, C. (2004). *Joint Canada/United States survey of health, 2002-03*. Catalogue number 82M0022XIE. [On-line]. Retrieved April 26, 2005 from the World Wide Web: <http://www.statscan.ca>.

Saunders, A. (2005). *Poverty group want free school breakfasts*. [On-line]. Retrieved August 16, 2005 from the World Wide Web: <http://www.stuff.co.NewZealand/stuff/print/0,1478,3378738a11,00.html>.

Schoen, C., Blendon, R.J., DesRoches, C.M., & Osborn, R. (2001). *Comparison of health care system views and experiences in five nations, 2001: Findings from The Commonwealth Fund 2001 International Health Policy Survey*. [On-line]. Retrieved October 17, 2004 from the World Wide Web: <http://www.cmwf.org>.

Schoen, C., Blendon, R.J., DesRoches, C.M., Osborn, R., Doty, M., & Downey, D. (2002). *New Zealand adults' health care system views and experiences, 2001*. Pub. no. 553. [On-line]. Retrieved October 17, 2004 from the World Wide Web: <http://www.cmwf.org>.

Schoen, C., & Doty, M.M. (2004). Inequities in access to medical care in five countries: Findings from the 2001 Commonwealth Fund International Health Policy Survey. *Health Policy*, 67, 309-322.

Scott, J. (1999). *Income Distribution in New Zealand – Key Statistics*. [On-line]. Retrieved February 1, 2003 from the World Wide Web: http://www.stats.govt.nz/domino/external/Web/prod_serv.nsf/

Siegrist, J., & Marmot, M. (2004). Health inequalities and the psychosocial environment – two scientific challenges. *Social Science & Medicine*, 58, 1463-1473.

Seniors Policies and Programs Database, (2005). *Income support benefits for seniors*. [On-line]. Retrieved April 29, 2005 from the World Wide Web: http://www.sppd.gc.ca/sppd-bdppa/sppd-bdppa/english/details.jsp?PROGRAM_ID=1808.

Statistics Canada. (1999a). *The Daily, Thursday, August 5, 1999. Seniors Income*. [On-line]. Retrieved March 3, 2002 from the World Wide Web: <http://www.statcan.ca/english/thedaily.htm>.

Statistics Canada. (1999b). *Selected Highlights From A Portrait of Seniors in Canada*. [On-line]. Retrieved March 3, 2002 from the World Wide Web: <http://www.statcan.ca/english/ads/89-519-XPE/hilites.htm>.

Statistics Canada. (1999c). *The Daily, Friday, October 1, 1999. A Portrait of Seniors in Canada*. [On-line]. Retrieved March 3, 2002 from the World Wide Web: <http://www.statcan.ca/english/thedaily.htm>.

Statistics Canada. (2000). *Women in Canada 2000: A guide to understanding the changing roles of women and men in Canada – Highlights*. [On-line]. Retrieved March 3, 2002 from the World Wide Web: <http://www.statcan.ca/english/ads/89-503-XPE/hilites.htm>.

Statistics Canada. (2004). *Life expectancy – abridged life table, at age 65 and confidence interval, by sex, Canada, provinces and territories, 2002*. [On-line]. Retrieved April 26, 2005 from the World Wide Web: <http://www.statcan.ca/english/freepub/84F0211XIE/2002/tables/>.

Statistics Canada. (2005a). *Persons on low income after tax, by prevalence in percent*. [On-line]. Retrieved March 26, 2005 from the World Wide Web: <http://www.statcan.ca/english/Pgdb/famil19a.htm>.

Statistics Canada. (2005b). *Incidence of low income among the population living in private households, by census metropolitan areas (1996 and 2001 censuses)*. [On-line]. Retrieved March 26, 2005 from the World Wide Web: <http://www.statcan.ca/englsih/Pgdb/famil60e.htm>.

Statistics New Zealand. (2000a). *Older People in New Zealand*. [On-line]. Retrieved February 1, 2003 from the World Wide Web: <http://www.stats.govt.nz/domino/external/Web/nzstories.nsf/>.

Statistics New Zealand. (2000b). *Population Ageing in New Zealand – Key Statistics*. [On-line]. Retrieved February 1, 2003 from the World Wide Web: http://www.stats.govt.nz/domino/external/Web/prod_serv.nsf/.

Statistics New Zealand. (2002a). *New Zealand census of population and dwellings 2001: Incomes*. Wellington: Statistics New Zealand.

Statistics New Zealand. (2002b). *Monitoring progress towards a sustainable New Zealand*. Wellington: Statistics New Zealand. [On-line]. Retrieved August 1, 2005 from the World Wide Web: <http://www.stats.govt.nz>.

Statistics New Zealand. (2004a). *New Zealand income survey: June 2004 quarter*. [On-line]. Retrieved May 3, 2005 from the World Wide Web: <http://www.stats.govt.nz>.

Statistics New Zealand. (2004b). *New Zealand life tables 2000-2002*. [On-line]. Retrieved April 26, 2005 from the World Wide Web: <http://www.stats.govt.nz>.

Statistics New Zealand. (2004c). *Extended families*. [On-line]. Retrieved May 3, 2005 from the World Wide Web: <http://www.stats.govt.nz/analytical-reports/maori/ext-fam.htm>.

Statistics New Zealand. (2005). *Older people in New Zealand: Household and living arrangements*. [On-line]. Retrieved March 29, 2005 from the World Wide Web: <http://www.stats.govt.nz/analytical-reports/older-people-in-nz/hh-liv-arngmt.htm>.

- Tannenbaum, C.B., & Mayo, N. (2003). Women's health priorities and perceptions of care: A survey to identify opportunities for improving preventive health care delivery for women. *Age and Ageing*, 32, 626-635.
- Tannenbaum, C.B., Nasmith, L., & Mayo, N. (2003). Understanding older women's health care concerns: A qualitative study. *Journal of Women & Aging*, 15(4), 103-116.
- Taylor, D., & Downer, C. (1997). Toward a women-centered health care system: Women's experiences, women's voices, women's needs. *Health Care for Women International*, 18, 407-422.
- van Kemenade, S. (2003). *Social capital as a health determinant: How is it defined?* Retrieved February 28, 2005 from the World Wide Web: <http://www.hc-sc.gc.ca/arad-draa>.
- Vayda, E., & Deber, R.B. (1984). The Canadian health care system: An overview. *Social Science & Medicine*, 18(3), 191-197.
- Watkins P.L., & Whaley, D. (2000). Gender role stressors and women's health. In R.M. Eisler & M. Hersen (Eds.), *Handbook of gender, culture and health* (pp. 43-62). New Jersey: Lawrence Erlbaum Associates.
- Wilkinson, R.G. (1996). *Unhealthy societies. The afflictions of inequality*. London: Routledge.

Williams, A.M., Forbes, D.A., Mitchell, J., Essar, M., & Corbett, B. (2003). The influence of income on the experience of informal caregiving: Policy implications. *Health Care for Women International, 24*, 280-291.

Wolfson, M.C., & Murphy, B.B. (1998). *New views on inequality trends in Canada and the United States*. Ottawa: Statistics Canada. [On-line]. Retrieved April 19, 2005 from the World Wide Web: <http://www.statcan.ca/english/research/>.

Wuest, J., Merrit-Gray, M., Berman, H., & Ford-Gilboe, M. (2002). Illuminating social determinants of women's health using grounded theory. *Health Care for Women International, 23*, 794-808.



Memorial

University of Newfoundland

Human Investigation Committee
Research and Graduate Studies
Faculty of Medicine
The Health Sciences Centre

Appendix 1

Ethical Approval

November 3, 2005

Reference #00.74

Dr. M. Murray
Community Health
2nd Floor, Health Sciences Centre

Dear Dr. Murray:

RE: "Norms & Narratives: A Study of Values Concerning Health and Illness in an Aging Population in Canada"

At the meeting held on **November 3, 2005**, the Human Investigation Committee reviewed your correspondence, dated October 13, 2005, which the Committee requested at the September 29, 2005 HIC meeting.

The Committee commented that as the primary objective has changed to a comparison, the research question has now changed.

The Committee granted retrospective approval of the amendment but prohibited the student from publishing her work in any medium other than the thesis since the data collected in New Zealand did not have ethical approval and objectives of the work changed significantly, all of which should have been reviewed and approved by the HIC in advance.

Sincerely,

John D. Harnett, MD, FRCPC
Co-Chair
Human Investigation Committee

Richard S. Neuman, PhD
Co-Chair
Human Investigation Committee

JDH;RSN\jjm

C Dr. C. Loomis, Vice-President (Research), MUN
Mr. W. Miller, Director of Planning & Research, HCCSJ

This form not to exceed one page in length.

Forward 1 copy of this form and any protocol for the amendment to: Human Investigation Committee, Room 1755, Health Science Centre.

Title of study. Include protocol number, if any.

HIC number:

Date: October 13, 2005

Norms and Narratives: A study of the attitudes and beliefs regarding health and healthcare of baby-boomers

Would you categorize the changes as minor (e.g. editorial, administrative and similar)	Yes	No
Will there be any increase in risk, discomfort or inconvenience to the participants?	Yes (Specify below)	No
Are there changes to inclusion or exclusion criteria?	Yes	No
Is a modification to the consent form required?	Yes (Append form)	No

Are there any significant changes to the original objectives? YES NO If so, **LIST** new objectives.

1. To compare the attitudes and beliefs of baby-boomers in Newfoundland with those in New Zealand

What is the rationale for the amendment(s)?

This amendment is to cover the revision of a subset of this project that investigated the health beliefs of low income women. The student had collected data for her thesis in St. John's prior to returning home to New Zealand. In the process of analyzing her data it became apparent that there were insufficient data for analysis. She has modified her thesis proposal to include a comparison with a small sample of New Zealand residents. All other details of the study remain unchanged.

Summarize the significant changes being requested. It is not necessary to itemize editorial, administrative and similar changes.

Study modification to include residents of New Zealand

Other pertinent information.

Michael Murray

Printed Name of Principal Investigator

Signature of Principal Investigator

Date

Appendix 2

Questions – initial

Tell me what health means to you...

Describe a healthy person...

What does it mean to be healthy?

What are your concerns for your future health care?

What do you see as problems that will affect your health care?

In yourself?

In the system?

What changes do you see happening to health care that will affect you?

What do you worry about regarding your health in the future?

How do you feel about the present system?

Changes...

Keep the same...

What do you expect from your future health care?

Existing services...

Non-existing services...

How does the Newfoundland and Labrador system compare to others in Canada?

Can you tell me about a positive experience you've had with the health care system?

Can you tell me about a negative experience you've had with the health care system?

When do you access the health care system?

Do you have difficulty accessing it when you need it?

How do you view accessibility as you age, over 65+?

Do you think about accessibility to services outside health care system?

Uninsured services...some medicines, elder care options, housing...

Do you think about where you will live, who will care for you, who will pay?

Affordability of elder care, nursing home, home care...

How have your life experiences affected your health?

What role does your community play in your health?

Where do you get your health information?

What role does your family play in your health?

What do you think of how health care issues are presented in the media; news, advertising, internet?

Appendix 3

Questions – final

Would you like to share any experiences you've had with the health care system?

Do you have any concerns for the future of health care?
What about for when you are over 65 years of age?

What are your personal expectations for health care?
How about for over 65 generally?

What do you envision your retirement to be like?

What would your ideal retirement be like?

What do you think are particular health concerns for low income women?

Do you think about where you might live, where you might like to live?

What role do you think friends and family play in your health care?

How do you think the community treats older people?

How do you want to be treated when you are over 65?

Appendix 4

Coding tree

Elderly issues

- Living arrangements
- Autonomy
- Reference to other cultures

Family

Health

- Dimensions – spirit, mental, physical
- Responsibility
- Food

Health care system

Medical staff

- Accountability
- Doctor shortage
- Care received

Drugs/pharmaceuticals

Preventive health

Accessibility

Waiting

Funding

Private health care

Income issues

Inequalities

- Richer can buy
- Health care system

Home care

Death

Palliative care

Future health concerns

Who will care for me?

Not being cared for

Health care system

Health

Expectations

Reference to the past – the way things were

Things specific to New Zealand or Newfoundland



