

# **The New Zealand Longitudinal Study of Ageing**

**Summary Report**

**- Caregiving -**

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## Introduction

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### New Zealand Caregiving Context

The New Zealand population is ageing overall and people are living longer leading to an increased prevalence of age-related morbidity, chronic illness, and disability. The number of caregivers has increased in New Zealand in line with the ageing population, with around 480,000 individuals in New Zealand providing care for someone who is ill or disabled. However, the proportion of caregivers in older age groups (55+) has increased at a faster rate than in the general population. The majority (93%) of New Zealanders aged 65 years and older live in private dwellings (Statistics New Zealand, 2007) suggesting that most older people with disabilities and high dependency on others will live in private households within the community (Dwyer, Gray, & Renwick, 2000). The provision of family-based in-home care for frail, ill, or disabled older people will become more prevalent.

Informal care provides many benefits including improved patient outcomes, and reduced unnecessary re-hospitalisations and residential care placements (Elliot & Parker, 2012; Miller & Weissert, 2000; Spillman & Long, 2009). There are also considerable financial benefits to society. Unpaid family caregiving is an essential part of the health system and save billions in health care expenditure each year. For instance, estimates of the annual economic value of informal caregiving range from £119 billion per year in the United Kingdom (Buckner & Yeandle, 2011) to \$US450 billion in the United States (Feinberg, Reinhard, Houser, & Choula, 2011). Providing such care publicly would not be economically sustainable.

*Health.* Caregiving is identified as a major stressor. Carers are more likely to suffer from adverse mental health outcomes such as depression, chronic stress, and anxiety compared to non-carers (Cochrane, Goering, & Rogers, 1997; Pinquart & Sorensen, 2003a; Pinquart & Sorensen, 2003b). National-level surveys and meta-analyses also show that family carers' physical health is worse than the rest of the population (Pinquart & Sorensen, 2003a; Vitaliano, Zhang, & Scanlan, 2003). The carer stress-health model proposes that psychological distress leads to physiological responses, which result in or exacerbate progression of illness (Vitaliano et al., 2003). In addition, psychological distress may interact with health behaviours increasing the risk of caregiver illnesses. Individual differences, such as vulnerabilities (e.g., gender, ethnicity) and resources (e.g., social support, financial resources) may also moderate the relationship between stressors and distress.

*Gender.* Caregiving is largely undertaken by women (Lee & Porteous, 2002; Singer, Biegel, & Ethridge, 2010), with women comprising nearly three quarters of all informal caregivers of older adults (Calasanti & Slevin, 2001). Female caregivers outnumber male caregivers in every age group in New Zealand (Department of Labour, 2011). Women also report higher levels of depression, more health problems and utilise more health care than men (Van de Velde, Bracke, & Levecque, 2010; Denton & Walters, 1999; Koopmans & Lamers, 2007) suggesting gender is potentially an important moderator of the caregiving-health relationship. Women tend to report greater caregiver burden than men (Barusch & Spaid, 1989) although differences are small.

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*Ethnicity.* Māori are more likely to provide family care than other ethnic groups in New Zealand with Māori females the most likely group undertaking this role (23% of all Māori women compared to 16% of New Zealand European women). There is little known about the role of ethnicity in caregiving-health relationship in New Zealand, although evidence from our previous longitudinal data suggests that Māori are more likely to provide care than non-Māori and that older Māori men providing high levels of care are at greater risk of poor mental health outcomes (Alpass, Pond, Stephens, Stevenson, Keeling & Towers, 2013). Ethnicity may interact with the caregiver-health relationship because of its relationship to health inequalities and structural disadvantage. Health disparities within the New Zealand population are well documented with Māori having poorer health outcomes, higher rates of chronic disease, and shorter life expectancy than other ethnic groups (Blakely, Tobias, Atkinson, Yeh, & Huang, 2007). The New Zealand Ministry of Health notes that both socioeconomic position and ethnicity contribute to these health inequalities through multiple pathways (Ministry of Health, 2006).

*Work.* A large proportion (65%) of those New Zealanders providing informal care are also in paid employment (Statistics New Zealand, 2006). The number of older people in the paid workforce is projected to increase in the next two decades (Statistics New Zealand, 2008), suggesting many carers will still be in paid work as they themselves age. Combining paid work and informal care is problematic for many carers and can impact on their health status and wellbeing (Korabik, Lero, & Whitehead, 2008). These competing roles may increase psychological distress and role overload (Salva, Almeida, Davey, & Zarit, 2008; Stephens, Townsend, Martire, & Drule, 2001). Work demands are not only associated with more compromised health and work-family conflict for working carers (Scharlach, 1994; Yildirim & Aycan, 2008), but they can also impact on work-related outcomes such as reduced work hours, absenteeism, and employment exit (Heitmüller & Inglis, 2007; Johnson & Lo Sasso, 2006).

## Summary

In sum, there is considerable evidence for the detrimental impact of providing care on wellbeing. With an ageing population the number of family members providing informal care for older people will also increase. The caregiver stress-health model suggests that certain groups of carers are potentially at higher risk than others for poor outcomes (e.g., women, Māori, those with low SES). In addition, an ageing population will mean an increasing number of caregivers will also be in paid employment. The combination of work and care may impact on not only health and wellbeing but also on work related outcomes including the ability to prepare for retirement. The emotional and physical wellbeing of older caregivers is therefore, of concern.

## Caregiving Activities of Older New Zealanders

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In 2010 and 2012 participants were asked to complete a questionnaire module on caring commitments.

### Caregiving Status

Participants were asked whether they provided care for someone with a long-term illness, disability or frailty (practical assistance for at least 3 hours a week). Three hundred

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and five (9.2%) participants were currently providing care, and 107 (3.2%) had provided care within the past 12 months to someone who had since died or moved into a nursing home or hospital (Figure 1). A further 453 (13.7%) had provided care for someone more than 12 months ago but did not actively care for them now. The majority of participants were not currently providing care and/or had not been providing unpaid care for someone in the past 12 months (73.9%).

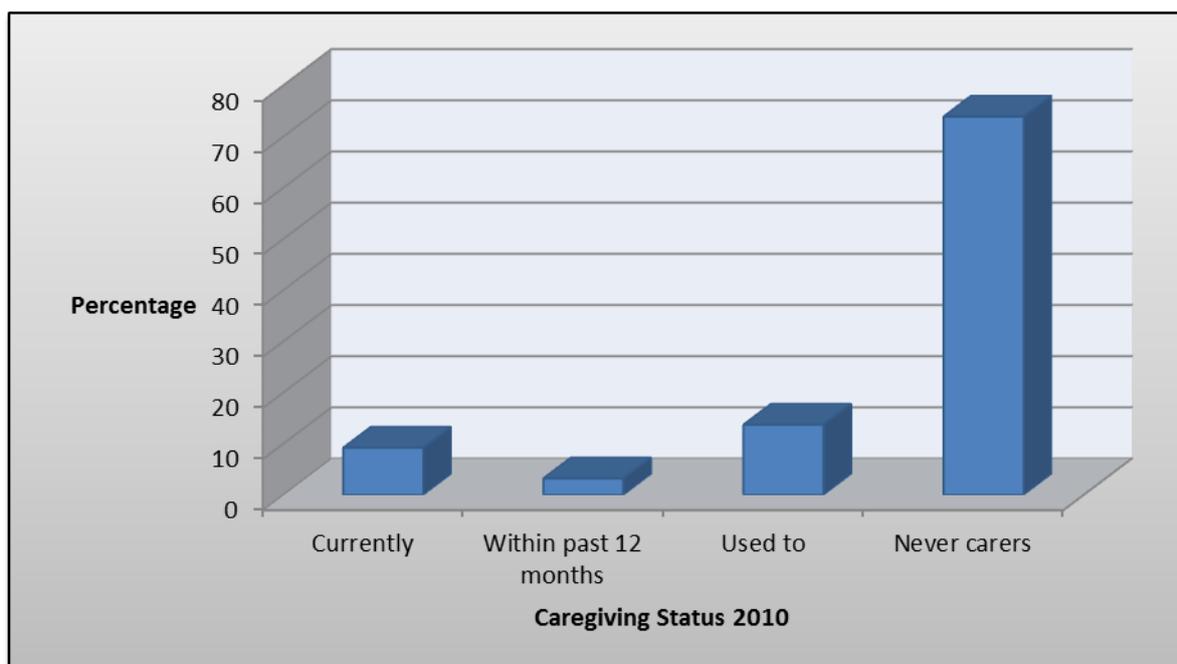


Figure 1. Caregiving status in 2010.

## Who Are The Carers?

As expected women were more likely to be caregivers than men (10.9% and 7.2% respectively,  $p < .001$ ). Carers tended to be younger (mean=62.53,  $sd=7.95$ ) than non-carers (mean=64.58,  $sd=8.08$ ),  $p < .001$  (Figure 2). Carers were also less likely to be in paid employment and more likely to be out of the paid workforce for reasons other than retirement (e.g. unable to work due to health or disability issue, full-time homemaker),  $p < .001$  (Figure 3). Economic standards of living also differed by caregiving status with carers more likely to be in severe or significant hardship than non-carers,  $p < .01$  (Figure 4). Contrary to previous New Zealand findings, Māori were no more likely to be currently providing care than non-Māori. Marital status, educational level and geographical location were unrelated to caregiving status.

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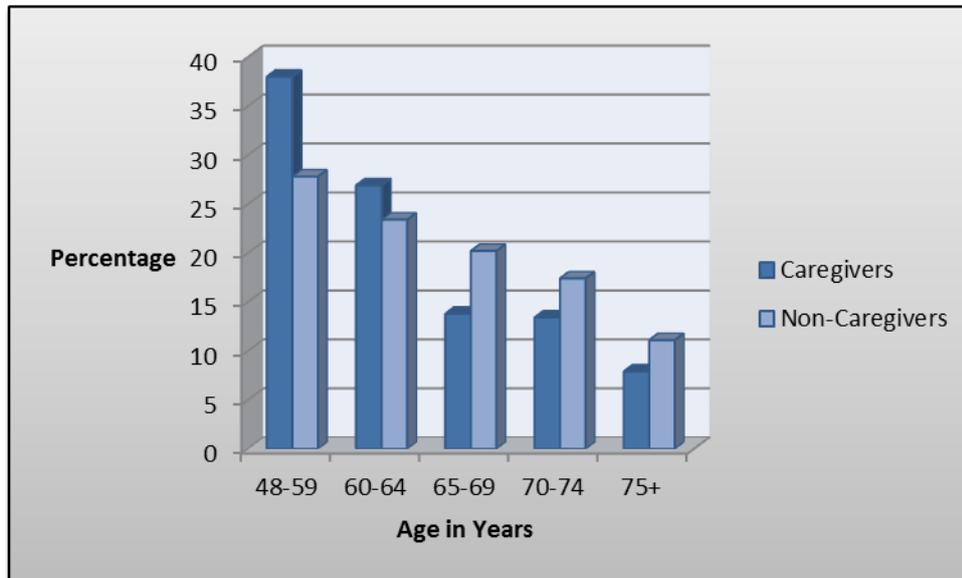


Figure 2. Caregiving status by age bands.

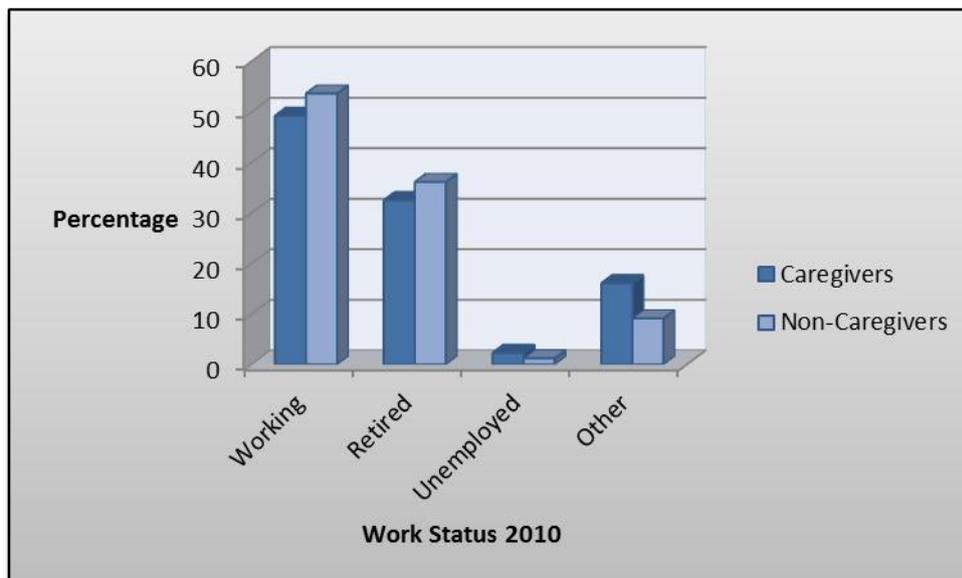


Figure 3. Caregiving status by work status.

## Caregiving

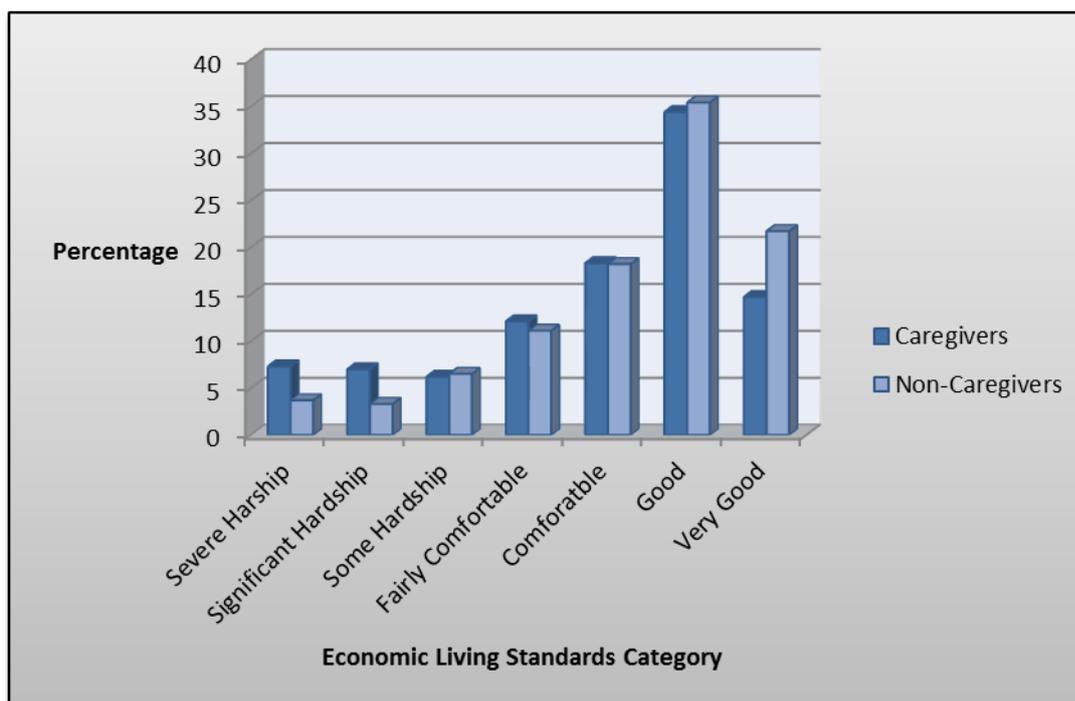


Figure 4. Caregiving status by economic living standards category.

### Who Are The Care Recipients?

The majority of carers provided care for only one person (83.3%). Care recipients ranged in age from 2 to 99 years with a mean age of 65.49 (sd=23.26) and a median age of 73 years. The time spent caring for the care recipient ranged from 1 month to 55 years (mean=6.35 years, sd=9.14). The majority of carers (59%) provided care every day with another 22% providing care several times per week (Figure 5). A quarter of the carers provided care all day and night but most provided care for between one and several hours on each caring occasion (Figure 6). Nearly a third were providing care for their spouse or partner (29.5%), 16.4% for a child and 28.2% for a parent or parent-in-law. Other care recipients included siblings and friends. Just over half the care recipients lived with their carer (50.5%), while 23.6% lived elsewhere alone, 8.9% lived elsewhere with others and 9.2% were in a residential or nursing facility. Participants reported on major medical conditions and/or disabilities of the care recipient necessitating the provision of care. The most frequently reported condition was “Frailty in old age” (38.4%) followed by mental health condition, stroke and respiratory condition (Figure 7). Forty percent of participants cited only one major medical condition for the care recipient, however just over thirty percent (30.3%) reported that the person they cared for experienced three or more conditions.

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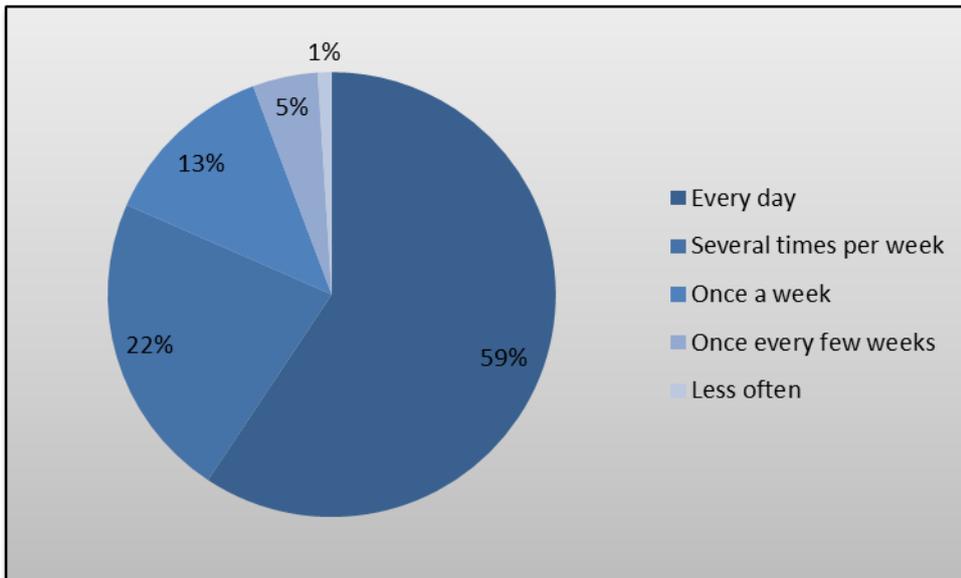


Figure 5. Frequency of caregiving.

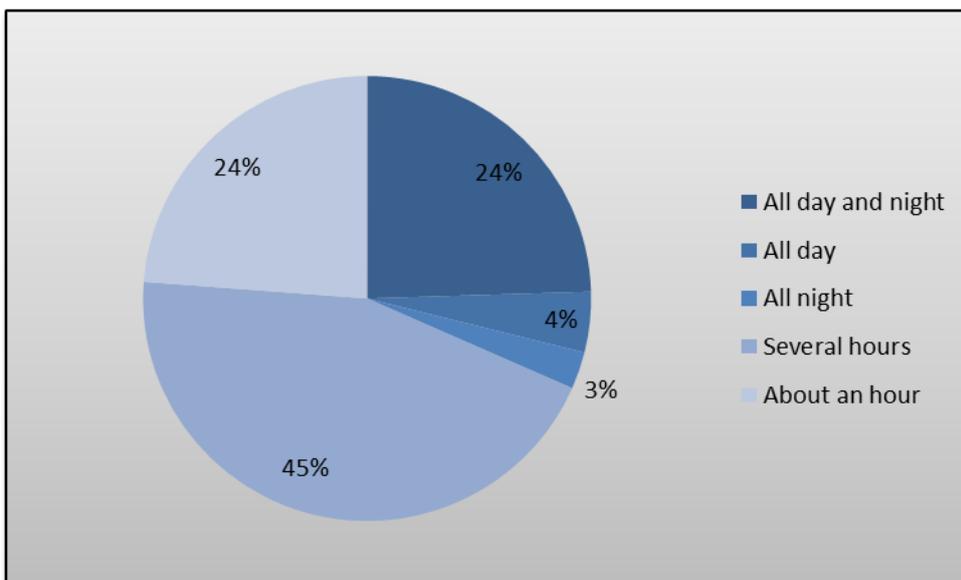


Figure 6. Time spent on caregiving.

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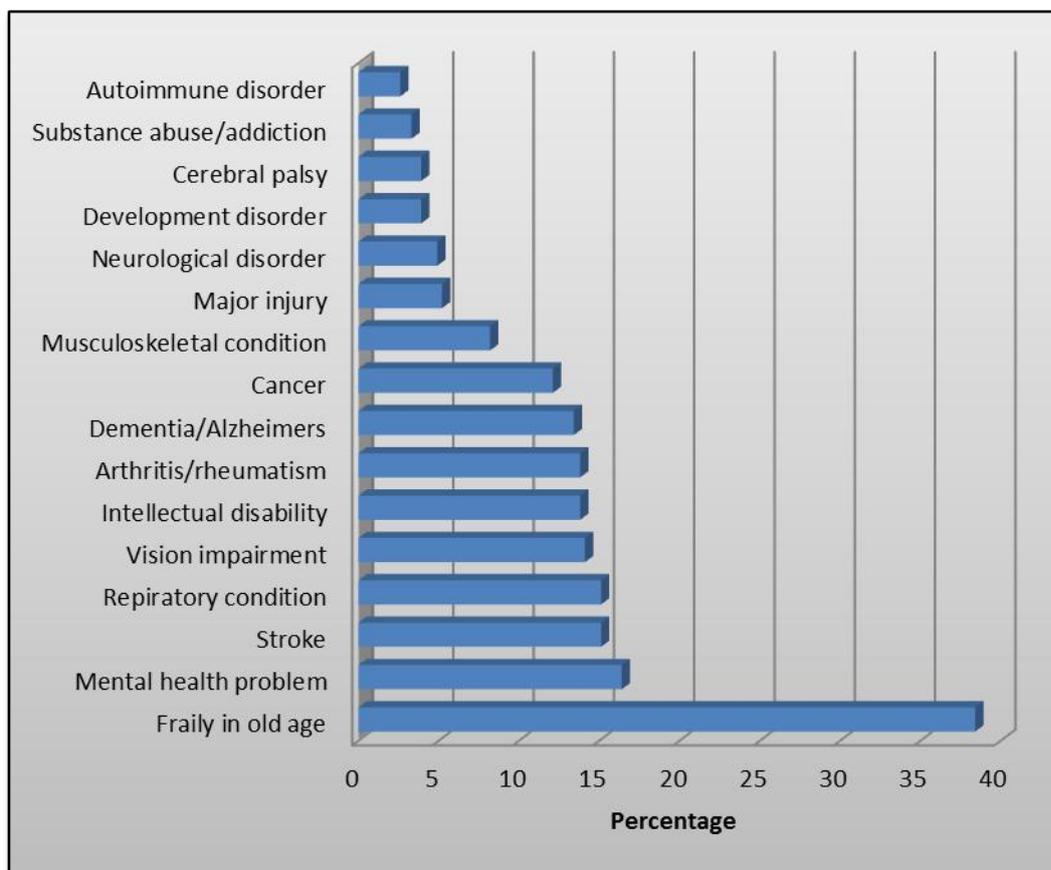


Figure 7. Major medical conditions or disabilities of the care recipient.

### Impact of Providing Care

When controlling for gender, work status and economic living standards, carers reported poorer mental health ( $p < .05$ ) compared to non-carers, however there was no significant difference between the two groups on physical health (Figure 8). Of those providing care, the more often care was provided and the more hours provided, the poorer physical health ( $r = -.18$  and  $r = -.22$ ,  $p < .001$  respectively). Frequency and time spent caring were unrelated to SF12 mental health scores, however the latter was positively related to depressive symptoms ( $r = .12$ ,  $p < .05$ ). As noted earlier women tend to experience more caregiver burden than men. In the present sample, we found that male caregivers reported poorer physical health than female carers, however this was accounted for by age, with male caregivers significantly older than female caregivers ( $p < .01$ ). There were no differences between male and female caregivers on mental health outcomes. Māori and non-Māori caregivers did not differ on physical health, however, Māori caregivers reported poorer mental health than non-Māori caregivers when controlling for age, work status and economic living standards (Figure 9).

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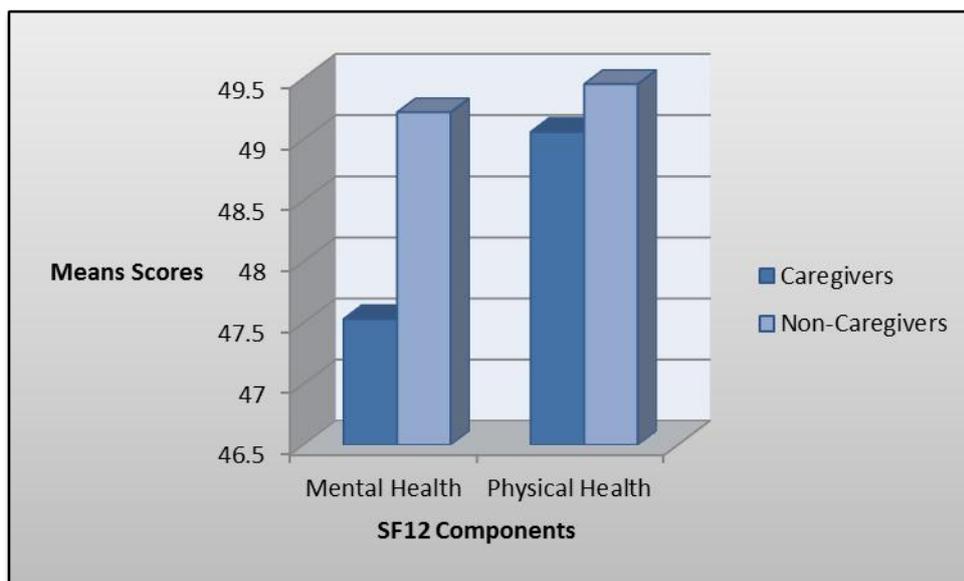


Figure 8. Mental and physical health by caregiver status.



Figure 9. Mental health for Māori and non-Māori by caregiver status.

## Care and Work

Examining the interaction of work and care, there were no differences in health between working and non-working caregivers when controlling for gender and economic living standards. Looking at those just in work there were no significant differences between caregivers and non-caregivers on job satisfaction or job stress, however caregivers were more likely to report that they could not afford to retire than non-caregivers,  $p < .01$ .

## Receiving Care and Support

All participants (including caregivers) were asked if they *personally* received any home-based care and/or support for themselves. Of the total sample of respondents, 118 (3.6%) received home-based help with meals, 137 (4.1%) with help with shopping, 205

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(6.2%) with housework, 330 (10.0%), with heavy household work such as gardening, 114 (3.4%) with looking after personal finances, 70 (2.1%) with personal care and 93 (2.8%) with communicating with other people such as doctors. This help was largely paid for by the participant or their family (Figure 10). Looking at those who identified as caregivers, only a small percentage of this group personally received care or support services for themselves (Figure 11).

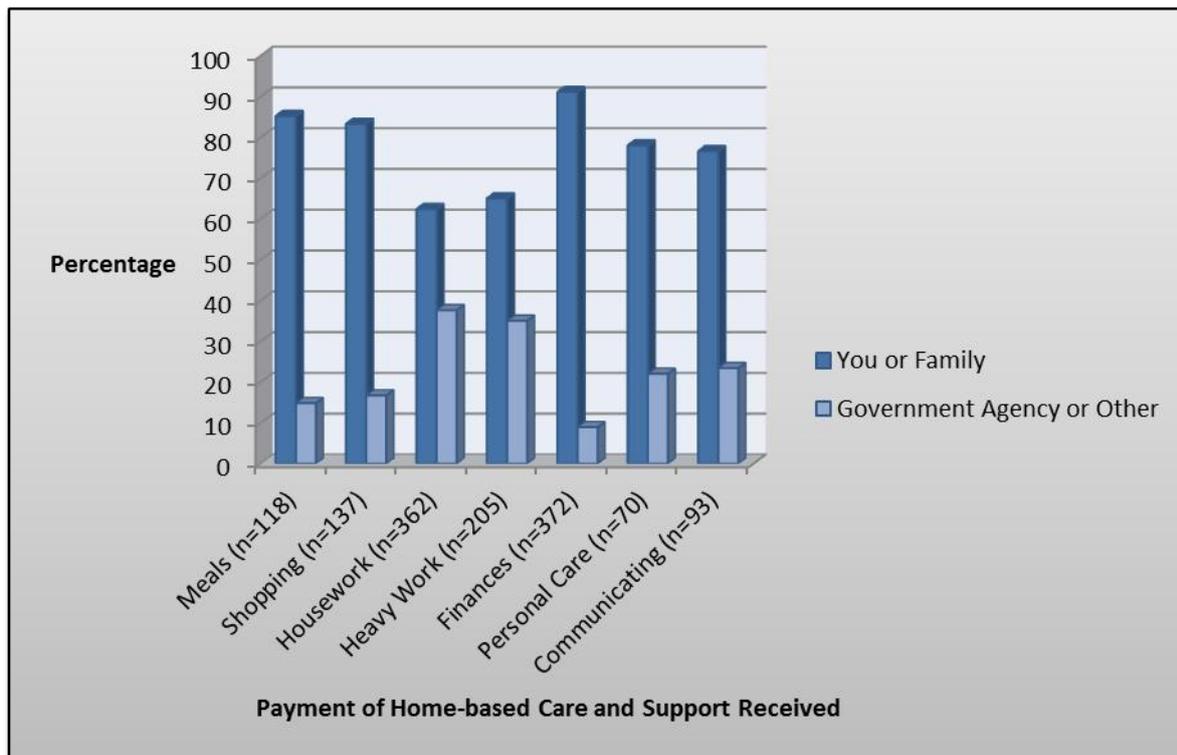


Figure 10. Home-based care and support personally received by all respondents.

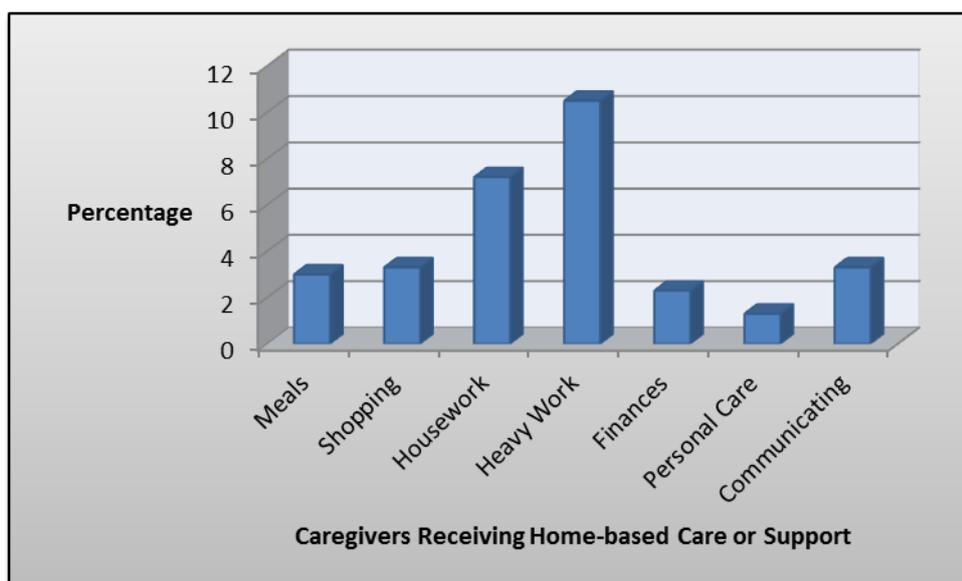


Figure 11. Home-based care and support personally received by caregivers.

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### Caregiving Transitions (2010-2012)

Participants were categorised into four groups: “Never”, for those who had not provided care at either wave; “Stopped”, for those who had stopped caregiving since wave 1; “Started”, for those who had taken up caregiving since wave 1; and “Continued”, for those who provided care in both waves. Women were more likely to have started and continued caring, while men were more likely to have not provided care at either wave (Figure 12).

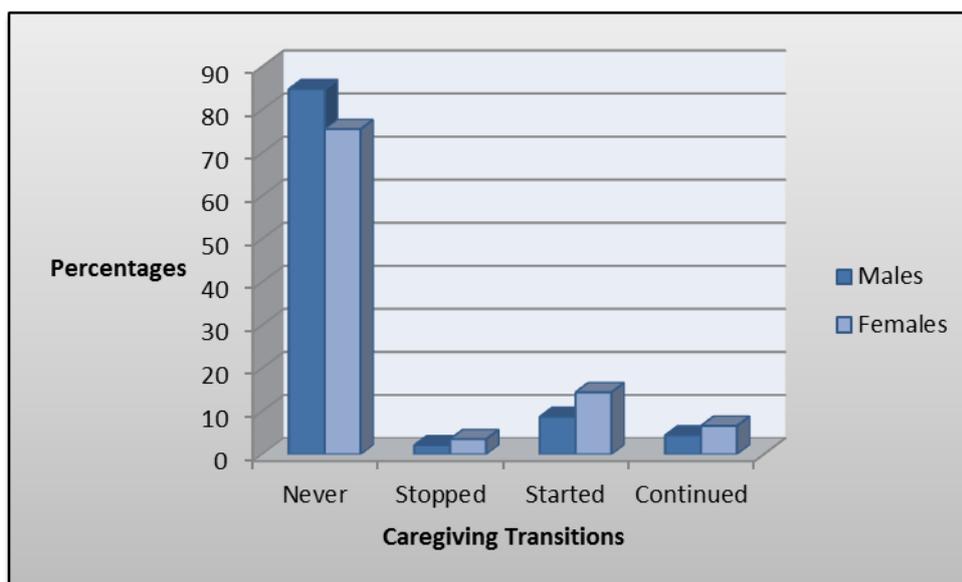


Figure 12. Caregiving transitions by gender.

Those in higher living standards categories were less likely to have started caregiving and more likely to have never provided care (Figure 13). Looking at health outcomes in 2012 across transition variables, there was no significant difference in physical health between the four transition groups. On mental health, the “Started” group reported significantly lower mental health scores in 2012 than the “Never” group when controlling for age, gender, work status and economic living standards, however this difference was accounted for by the poorer mental health in 2010 for the “Started” group (Figure 14). More interestingly when looking at *change* in health between waves, we see that the “Stopped” group experience the most change in health particularly in mental health where around 20% experienced an increase in mental health scores.

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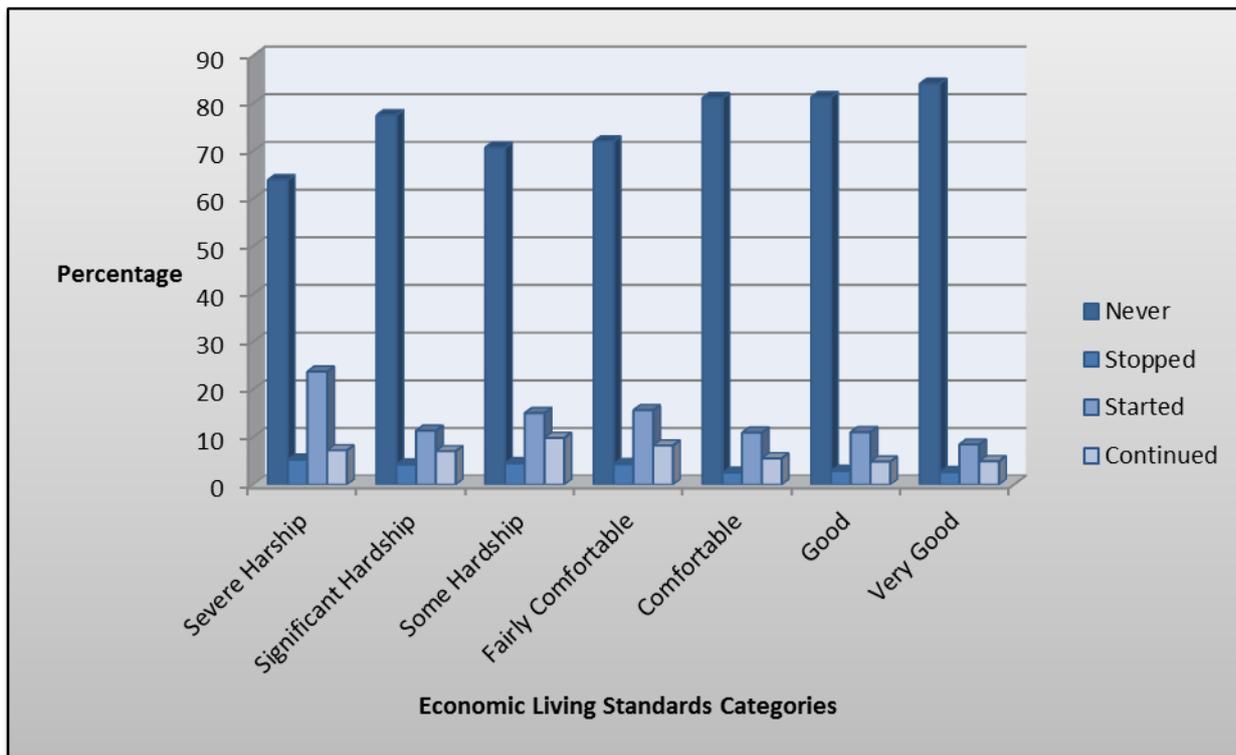


Figure 13. Caregiving transitions by economic living standards categories.

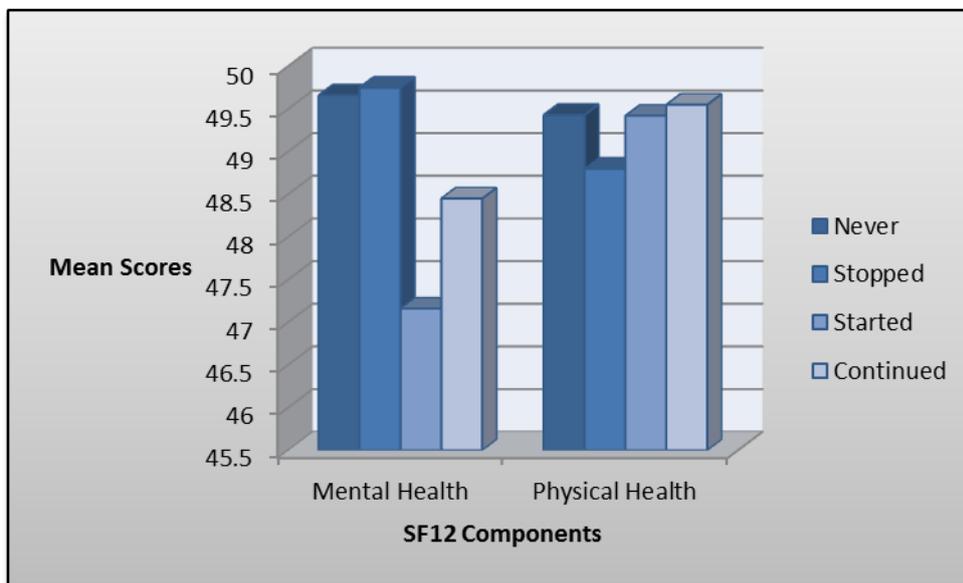


Figure 14. Caregiving transitions by SF12 health component scores.

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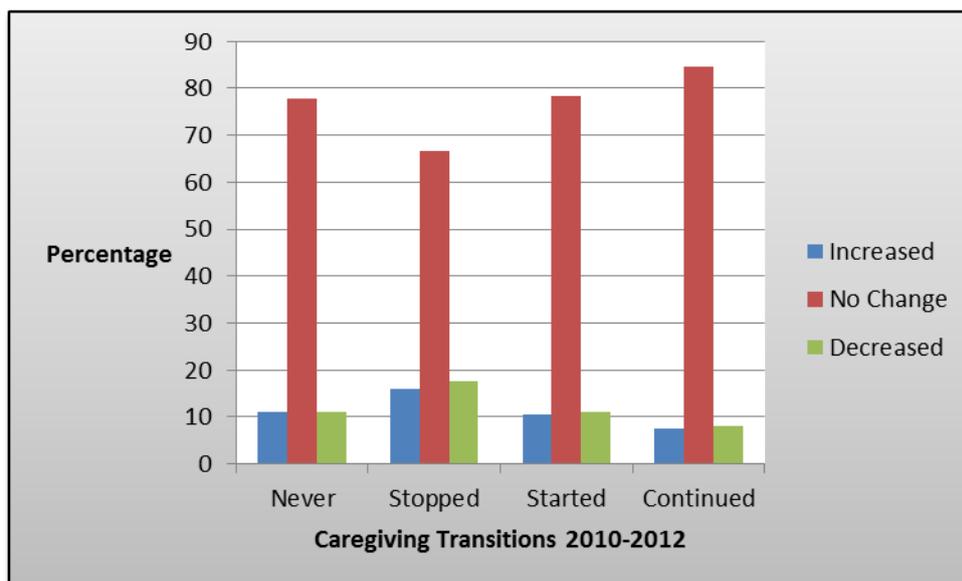


Figure 15. Change in physical health scores by caregiving transition (change represents an increase/decrease by at least one standard deviation).

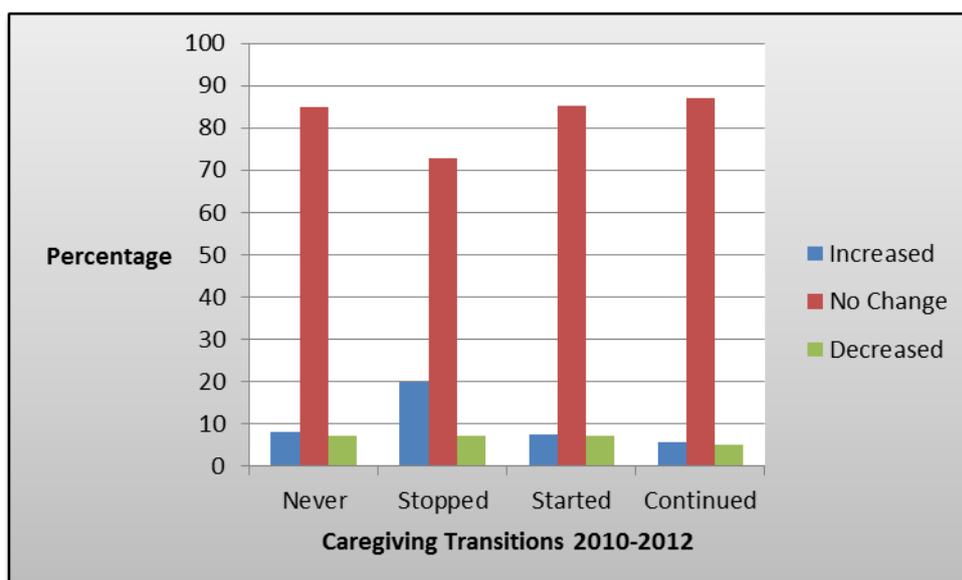


Figure 16. Change in mental health scores by caregiving transition (change represents an increase/decrease by at least one standard deviation).

## Summary and Concluding Comments

A significant proportion of the NZLSA sample were either currently providing care (9.2%), had done so in the past 12 months (3.2%) or more than 12 months prior to survey (13.7%). This compares to 15.2% of the population aged 15 years and over in the 2006 census who provided care and 16.1% of those aged 50+.

Frailty in old age was the most common condition reported for care recipients with nearly 40% of caregivers citing this condition. A significant proportion of the sample were

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caring for older parents or in-laws (28%). Participants in the current study provided simple yes/no self-reports of care recipient conditions. A recent study examining the prevalence of frailty in European countries using more in-depth measures and physiological biomarkers of frailty, found a pre-frailty rate for middle-aged (50 to 64 years) community dwelling adults of 37.4% and a frailty rate of 4.1% (Santos-Eggimann, Cuenoud, Spagnoli & Junod, 2009). For those 65 and over the rates were 42.3% and 17% respectively. These rates would suggest that basic self-report proxy measures of frailty may be valid for postal-based surveys such as ours.

Carers did report poorer mental health as expected (when controlling for important demographic variables), but there was no significant difference between the two groups on physical health. However, burden of care was related to physical health with those providing more hours of care on more occasions reporting the poorest health. As noted earlier female caregivers outnumber male caregivers in every age group in New Zealand (Department of Labour, 2011) and this was also found in the NZLSA sample with women more likely to be caregivers than men (10.9% and 7.2% respectively) at both waves. We found no differences between these male and female caregivers on mental health however contrary to previous findings (Barusch & Spaid, 1989), we found male caregivers reported poorer physical health. Further analyses showed that male caregivers tended to be older than their female counterparts and older age was related to poorer health.

It is argued that caregiving is an ingrained value in Māori culture (Collins & Willson, 2008). Most older Māori remain in family households as they age with very few residing in residential care (Ministry of Health, 2004) and census data show that Māori are more likely to provide family care than other ethnic groups in New Zealand (Statistics New Zealand, 2013). However in the NZLSA sample, the proportion of each group currently providing care was similar. The census data includes caregivers aged 15 years and older and the Māori population is much younger than the total population which may account for the different findings.

Collins and Willson (2008) have suggested that the role of caregiver may have greater negative impacts on older Māori compared with other groups because of their likely poorer health status. In the NZLSA sample Māori and non-Māori caregivers did not differ on reported physical health, however Māori caregivers did report poorer mental health when controlling for age, work status and economic living standards. Collins and Willson (2008) note that Māori with disabilities prefer informal over formal care and support systems suggesting Māori may not have access to formal resources and support that may mitigate the negative consequences of providing care. The authors argue that many Māori “experience some degree of compromised access, use, effectiveness, and quality of health services” (pg.30). Frustration with barriers to accessing formal care systems and the lack of responsiveness by these systems to Māori health needs have been noted elsewhere (Durie et al., 1997). Interactions with health care systems may result in many older Māori caregivers not receiving the formal support services they are entitled to that may ease the burden of family caregiving. In addition, the multiple roles of elder Māori may also impact on caregiver health and wellbeing. Collins and Willson (2008) note that kaumātua are often heavily involved in Māori society and that the scope of these roles tends to increase with age. Durie et al. (1997) noted in their research on the health and wellbeing of older Māori, that 16% of kaumātua felt overburdened by their roles, suggesting additional supports, responsive to the needs of older Māori caregivers, would be appropriate.

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Although 54.8% of carers were in some form of paid employment, carers were less likely to be in paid employment than non-carers and more likely to be out of the paid workforce for reasons other than retirement (e.g. unable to work due to health or disability issue, full-time homemaker). Previous research has found that combining work and care can have detrimental impacts on both health and work-related outcomes (Korabik et al., 2008; Salva et al., 2008; Stephens et al., 2001; Heitmueller & Inglis, 2007; Johnson & Lo Sasso, 2006). In the NZLSA sample workers were in better health than non-workers, however there were no differences in health between working and non-working caregivers when controlling for gender and economic living standards. Caregivers were more likely to report that they could not afford to retire and this was also reflected in the finding that carers were also more likely to be in severe or significant hardship than non-carers, and less likely to be in paid employment.

Looking at changes in health status over the two year timeframe, the group who had stopped caregiving by time two were more likely to report change in health status (either decline or improve) than no change compared to other transition groups. This suggests that this group may include those who have relinquished the caregiving role due to their own failing health along with those whose care recipient no longer requires care (i.e. recipient died, was institutionalised or their condition improved). Previous research has found that cessation of caregiving due to the death or institutionalisation of the care recipient can have health benefits for the caregiver (Bond, Clark & Davies, 2003; Grant, Adler, Patterson et al., 2002). It should be noted that the majority in each transition group reported no change to physical and mental health between waves and this may be a function of the short timeframe (2 years) and the relatively young age of the youngest in the sample at the time of data collection (48 years at time one). That is, major health and functioning declines are less likely to occur in such a short time in the younger cohort.

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