

# CAREGIVER STRESS ACROSS DIFFERENT DEMENTIA TYPES

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Science in Psychology

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## Abstract

Research examining the risk factors of caregiver stress has included various populations treating caregivers as a homogenous group. This can dilute possible effects of disorder specific risk factors. Recently, the literature has examined caregiver stress across neurological diseases. This study aimed to describe and compare four groups of community based New Zealanders (Parkinson's disease = PD; Parkinson's disease with dementia = PDD; Alzheimer's disease and related dementias = AD+; and a control group = ND) and their caregivers in terms of demographic, functional, neuropsychiatric and psychosocial risk factors for caregiver stress.

Anonymised data from the New Zealand InterRAI-HC was used. A total of 66266 clients were included in the analyses. Caregivers who expressed feelings of distress, anger or depression were categorised as experiencing stress. Chi-square and logistic regression analyses were used. A total of five hierarchical logistic regressions were run; one for each group; and one regression containing the diagnostic groups as predictor variables.

Caregivers in the PDD group spent more hours caregiving and provided more support with activities of daily living compared to caregivers in other groups. The proportion of caregivers experiencing stress was significantly higher in the PDD group compared to all other groups (PDD = 36%; AD+ = 31%; PD = 21%; ND = 15%;  $\chi^2 = 1859.3$ ,  $p < .001$ ). When controlling for covariates, this result was not upheld in logistic regressions; instead, caring for clients with Alzheimer's disease or related dementia increased the odds of caregiver stress by 15%. Logistic regressions contained 28 predictors and explained between 11-24% of variance in caregiver stress. Including psychosocial predictors explained a small but significant amount of variance in caregiver stress.

The results did not show a clear pattern of risk factors established in the literature, which could be due to a power problem and/or sample size imbalance across groups. While clients in the PDD group had more complex needs, the study showed that caregivers of clients with different neurological conditions face unique challenges and it remains unclear whether these challenges are reflected in caregiver stress.

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Comparing caregiver stress of home care clients with different dementia types using the New Zealand version of the International Residents Assessment Instrument

When an older person's health deteriorates, informal caregivers are at the forefront of ensuring their loved one's unique needs are met. In 2013, over 400,000 informal carers in New Zealand spent around 672.2 million hours caring for their families and friends. This benefitted the country around 5% of its Gross Domestic Product (Grimmond, 2014; Ministry of Social Development, 2014). These, primarily untrained, spouses, relatives or friends, not only provided assistance with personal care, domestic tasks or emotional support (Carretero, Garcés, Ródenas, & Sanjosé, 2009), but also assisted with medication administration, care coordination, and surveillance of falls (Mosley, Moodie, & Dissanayaka, 2017). It is important to understand sources of carer stress in order to ensure that loved ones receive the best quality of care, and that informal caregivers maintain their sense of overall wellbeing.

Caregiving can take a toll on many aspects of an informal carer's functioning, including physical and psychological health. A large body of research has been conducted to elucidate contributors of carer stress (Carretero, Garcés, Ródenas, & Sanjosé, 2009; Mosley et al., 2017); however, most studies treat caregivers as a homogenous group, comparing caregivers to non-caregivers on indicators of physical and psychological functioning. More recently, studies have started to differentiate between dementia and non-dementia caregivers due to evidence suggesting that adverse health effects are more pronounced in dementia caregivers (Pinquart & Sörensen, 2003). In 2016, an estimated 62,287 New Zealanders lived with dementia (Deloitte, 2017), which was a 29% increase from the year 2011. Depending on the underlying pathology, the experience of dementia can be highly variable for the person with the disease and their caregivers. Despite this knowledge, limited research has been done to investigate differences in stress experienced by carers of clients with different diseases

underlying a dementia, such as Parkinson's disease. While past research has focused on Parkinson's disease as a whole, more recent literature suggests that it is worthwhile to make a distinction between those caring for someone with and without dementia (Leroi, McDonald, Pantula, & Harbishettar, 2012).

This study examined carer and client characteristics in a sample of home based New Zealanders with significant health needs. To describe such characteristics and to elucidate individual risk factors of carer stress, the sample was subdivided into four client groups. These were clients with Parkinson's disease with and without dementia (PDD & PD), a group of clients diagnosed with Alzheimer's disease and related dementias (AD+), and a control group (ND) of clients with significant health issues but without any of the neurological diseases mentioned above. The data for this study stemmed from the International Residents Assessment Instrument for Home Care clients (InterRAI-HC), which is a multidisciplinary diagnostic tool that focuses on needs and care coordination of community based older persons. After a period of piloting the InterRAI-HC in 2004, District Health Boards in New Zealand have used the assessment since 2012, and since 2015, it has been made mandatory across the country. Currently, New Zealand is the only country worldwide that has implemented the InterRAI-HC nationwide (Schluter et al., 2016).

### **Parkinson's disease**

The motor disorder Parkinson's disease is the second most common neurodegenerative disease in the world and is characterised by fluctuating motor and non-motor symptoms. Common motor symptoms include resting tremor (shaking), rigidity, bradykinesia (impaired ability to move swiftly) and postural instability (Aarsland, Zaccari, & Brayne, 2005; Chaudhuri, Healy, & Schapira, 2006). Non-motor symptoms are clinically more pronounced and encompass cognitive impairment, behavioural manifestations and neuropsychiatric symptoms including depression, anxiety, apathy, sleep disturbances and psychosis (Jankovic,

2008). Incidence rates for Parkinson's disease have been found to increase with male gender (Riedel, Bitters, Amann, Garbe, & Langner, 2016) and age, with an estimate of 0.3 per 1000 person-years for people aged 55-65 years and 4.4 per 1000 person-years for those aged 85 and over (Aarsland et al., 2001; Lau et al., 2004).

Longitudinal studies estimate that approximately 80% of individuals with Parkinson's disease are at risk of dementia (Jankovic, 2008), and epidemiological studies suggest that approximately 40% of individuals with the disease, progress to having some form of dementia (Aarsland et al., 2001; Chaudhuri et al., 2006; Emre, 2003). The World Health Organisation has defined dementia as a chronic and progressive syndrome caused by a disease of the brain that manifests as cognitive impairment in processes such as memory, comprehension, language, judgment and general thinking. Additionally, deterioration in emotional control, social behaviour and motivation often co-occur (WHO, 1992 as cited in The Ministry of Health, 2013). As cognition declines, so does one's ability to perform activities of daily living, which eventually requires the help and support from informal carers. In order for clients to remain in living in the community it is crucial to minimise caregiver stress.

While there is substantial overlap in pathology, recent genetic, neurochemical, neuroimaging and neuropathological evidence has emerged showing differences between different dementias, for example, dementias caused by Parkinson's disease and Alzheimer's disease. (Farlow & Cummings, 2008). Alzheimer's disease is the most common type of dementia accounting for 60-90% of dementia diagnoses. This amnesic type of dementia predominantly presents with impairments in short-term memory, learning, sensory processing and language (Noe et al., 2004), and is clinically distinct to cognitive decline in Parkinson's disease. In contrast, Parkinson's disease accounts for approximately 4% of dementias (Aarsland et al., 2005), and is characterised by attentional fluctuation, impairments in

executive function, visuospatial abilities and language retrieval as well as amplified neuropsychiatric symptoms (e.g. psychosis, sleep disturbance). Parkinson's disease patients with and without dementia have comparable motor symptoms, irrespective of the presence of dementia; hence, the disease lends itself to comparing dementia with non-dementia caregivers. Given different clinical presentations across dementia subtypes and level of cognition, the question arises whether differences in pathology and clinical presentation have an effect on carer stress.

### **Caregiving**

Caring for a family member or friend in addition to one's own employment and family obligations, likely increases stress in a carer's life. While most people arguably are able to cope with short-term stress, long-term caregiving for clients with progressive diseases exposes carers to chronic stress, which is associated with adverse health outcomes (Cohen, Colantonio, & Vernich, 2002). It has been argued that dementia caregiving is uniquely stressful and has a larger adverse impact on caregiver wellbeing compared to non-dementia caregiving (Pinquart & Sörensen, 2003; Schoenmakers, Buntinx, & Lepeleire, 2009). Dementia caregiving has been consistently related to a number of negative outcomes such as reduced quality of life, more symptoms of depression, anxiety, stress and burden (Ask et al., 2014; Pinquart & Sörensen, 2003). Some studies suggest that behavioural and psychological symptoms of dementia are correlated more strongly with the narrower construct of depression than with the broader construct of caregiver burden (Black & Almeida, 2004; Mercer, 2015).

Aside from physical and psychological strain, it has been found that dementia carers' immune function also becomes compromised compared to matched controls (Kiecolt-Glaser et al., 1987). Dementia-specific stressors that may help explain the larger burden observed, include forgetfulness, confusion, agitation, resistance of care and other problem behaviours. Other distinct stressors that acknowledge the progressive nature of the disease, include the

compromised ability to express gratitude to their caregivers and the unlikelihood for caregivers to witness positive effects of their caregiving efforts (Pinquart & Sörensen, 2003).

Caregiver stress might vary by level of cognitive impairment. In the case of Parkinson's disease, Leroi et al. (2012) reported that caregiver burden was worse when clients experienced dementia versus clients who only had mild or no cognitive impairment. To date, limited research has investigated whether the underlying disease that causes dementia is predictive of carer stress, and evidence appears to be mixed. Some research suggests that caregivers of clients with Parkinson's disease related dementia experience more stress than caregivers of clients with Alzheimer's disease related dementia (Lee, McKeith, Mosimann, Ghosh-Nodiyal, & Thomas, 2013; Shin et al., 2012; Svendsboe et al., 2016). In contrast, research by Mitchell et al. (2015) found the opposite; however, they did not examine varying levels of cognition in their Parkinson's disease sample. The following will review the literature on caregiver and client characteristics, and how they relate to caregiver stress.

### **Caregiver characteristics**

Caregiver characteristics and their relationship to carer stress have been studied within the wider caregiver literature rather than specifically in Parkinson's disease. In terms of caregiver demographic characteristics, a meta-analysis by Pinquart and Sörensen (2006) that included 229 studies relating to dementia and non-dementia caregivers, found that gender explained less than 2% of caregiver burden and depression. Female caregivers had higher levels of depression and caregiver burden as well as lower levels of subjective wellbeing and physical health than their male counterparts. One Parkinson's disease specific meta-analysis, including 10 studies, was unable to include caregiver gender in their analyses (Lau & Au, 2011), and another only reported a trend, with female caregivers reporting more stress than male caregivers (Leiknes, Lien, & Severinsson, 2015). Lau and Au (2011) included caregiver age, which yielded inconsistent findings in relation to carer stress.

In another meta-analysis, Pinquart and Sörensen (2011) examined caregiver type and compared spouse, child and child-in law caregiver outcomes across 168 studies of dementia and non-dementia caregivers. They only found differences between spouse and child caregivers on domain specific, rather than global measures of caregiver burden (e.g. physical). In their sample, spouses provided more support, had a higher rate of depression, more financial hardship, and lower levels of psychological wellbeing than child and child-in law caregivers. Authors of a Parkinson's disease specific systematic review, which included 31 studies, suggested that whilst most of their studies included a description of caregiver types (spouses, children, friends etc.), many were unable to include these in their analyses due to small sample sizes and consequently, the evidence on carer stress for certain caregiver groups is sparse (Leiknes, Lien, & Severinsson, 2015).

The researchers recommended caregiver subgroup analyses to enable more differentiated and targeted clinical practice, should at-risk groups emerge. Adult children have to juggle multiple roles such as caregiving, career responsibilities, children and their own spouses, but positive aspects from caring such as enjoying time together, becoming closer, and giving back care, may counteract the effects of juggling multiple roles (Habermann, Hines, & Davis, 2013). Spouses may experience more burden than children due to a multitude of factors such as their own declining health, co-habitation, and changing partnership dynamics (Pinquart & Sörensen, 2003; Viwattanakulvanid et al., 2014).

Another factor that is important but that has not received as much attention in the caregiving literature is co-habitation. It is not difficult to imagine that being a live-in caregiver could lead to more carer stress due to less downtime compared to a caregiver who is able to leave at the end of the day. Despite Pinquart and Sörensen (2003) suggesting that co-habitation is an important factor to include in analyses, there is limited research that has included this variable in statistical analyses (Pinquart & Sörensen, 2007; Shin et al., 2012). A

large meta-analysis covering the wider caregiving literature contained 176 studies, and was only able to include 11 studies relating to co-habitation (Pinquart & Sörensen, 2007). They found that co-habitation had a worse effect on physical compared to mental health. This was reflected in a Parkinson's disease specific systematic review containing a total of 29 studies, with only one of the studies focusing on caregiver living arrangements, and which found no evidence of a predictive relationship to carer stress (Greenwell, Gray, van Wersch, van Schaik, & Walker, 2015).

While co-habitation implies the lack of downtime for a caregiver, the total amount of time spent caregiving is also an important factor to consider. There is mixed evidence regarding the amount of time spent caregiving and the impact this has on caregiver stress, with some studies finding a significant association (Zhong, Peppard, Velakoulis, & Evans, 2016), and others not (Martínez-Martín et al., 2007; Shin et al., 2012). In their Parkinson's disease specific systematic review, Greenwell et al. (2015) found an association between hours of care and carer burden but not depression. Moreover, it has been proposed that this association may be mediated by factors such as perceived support, or moderated by perceived burden (Goldsworthy & Knowles, 2008). That is, when carers are already burdened, their negative perception of time spent caring is amplified (Zhong et al., 2016). Jones et al. (2017) found that caregivers of clients with Parkinson's disease with dementia provided more hours of care compared to those without dementia.

Some researchers have examined the impact of the number of tasks caregivers assist their loved ones with, on caregiver stress, and findings suggest that it is a predictor of stress (Drutyte, Forjaz, Rodriguez-Blazquez, Martinez-Martin, & Breen, 2014). While the quantity of time spent caregiving appears to make an impact on carer stress, it may also be helpful to differentiate between arguably lighter caregiving activities such instrumental activities of

daily living (shopping, meal preparation, housework) and more intensive activities of daily living (personal cares, mobility support).

### **Client characteristics**

In terms of client demographic characteristics, Leiknes et al. (2015), in their Parkinson's disease specific systematic review including 31 studies, found client gender had little impact on caregiver stress. However, they did observe a trend in studies, whereby the combination of male client gender and female caregiver was associated with increased carer stress. Another systematic review found male client gender only to be associated with carer stress when the outcome variable was related to mental health but not caregiver burden (Greenwell et al., 2015). In the review by Leiknes et al. (2015), age was only associated with carer stress when analysed by age groups, and in the Greenwell et al. (2015) review, it was only related to caregiver mental health but not caregiver burden. Older clients may have other health problems in addition to Parkinson's disease that contribute to increased caregiver stress (Martínez-Martín et al., 2007). Marital and financial status were rarely addressed in studies and were not related to caregiver stress (Greenwell et al., 2015; Leiknes et al., 2015).

### **Functional status.**

For the purpose of this thesis, functional status refers to a cluster of related symptoms including cognitive status, motor symptoms, falls and activities of daily living. Impaired cognitive functioning in clients with Parkinson's disease particularly comprises executive, visuospatial, and mnemonic skills. It is associated with carer stress possibly due to increased motor impairment and associated functional dependence (Scharre et al., 2016). The overall finding of a meta-analysis suggests that poorer cognitive function relates to burden in caregivers of clients with Parkinson's disease (Lau & Au, 2011). However, studies within the meta-analysis were inconsistent, and results appeared to be dependent on the reliability of the measures used to determine cognitive impairment and caregiver stress.

A more recent study found that caregiver stress increased incrementally as cognitive function declined across clients classified as normal cognitive function, mild cognitive impairment and dementia (Jones et al., 2017). Cognitive fluctuation refers to decline or improvement of cognitive function during the course of a day (Sun et al., 2018). It is reported to predict carer stress more consistently than general cognitive function (Lee et al., 2013; Mercer, 2015; Scharre et al., 2016). It has been shown that the associated unpredictability with regards to daily routines and activity scheduling in particular operates as a source of stress and frustration for carers (Mercer, 2015). Compared to clients with Alzheimer's disease, short-term memory difficulties in clients with Parkinson's disease related dementia, are not as severe (Bosboom, Stoffers, & Wolters, 2004).

Progressively worsening motor symptoms in clients with Parkinson's disease, such as freezing of gait, speech disturbance and postural instability fluctuate daily and require caregivers to be vigilant and repeatedly encourage safety behaviours, which in turn, may increase worry and strain (Roland, Jenkins, & Johnson, 2010). Most literature reviews concluded that when compared with non-motor symptoms (Leiknes et al., 2015; Leroi et al., 2012), motor impairment seems to play a minor part in predicting caregiver stress (Greenwell et al., 2015; Lee, McKeith, Mosimann, Ghosh-Nodyal, & Thomas, 2013). However, in Lau and Au's meta-analysis (2011), motor symptoms were moderately strong predictors of caregiver stress. Motor symptoms may impact on carer wellbeing due to the fluctuation of motor symptoms, which lead to worrying, ongoing surveillance to prevent injury and inability to plan outings. Therefore, it may be the mental aspects associated with motor symptoms that impact on carer stress (Mercer, 2015).

Research has shown that approximately 36% of patients with Parkinson's disease report the occurrence of falls (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006), with impaired motor function being a major contributor (Roland & Chappell, 2014). Despite being a key

variable of functional impairment in patients with Parkinson's disease, a review by Leiknes et al. (2015) noted that only few studies have examined its contributory effects on caregiver stress. Caregiver demands may be exacerbated by a number of factors related to falls. For instance, the risk of future falls may impose the need for constant vigilance upon the caregiver. Physical injuries and ambulatory anxiety are examples of physical and psychological consequences of falls that can escalate dependence on the caregiver (Roland et al., 2010).

Motor and cognitive deterioration both contribute to the degree of functional impairment, and whilst not unique, they are highly relevant to Parkinson's disease. Due to motor and cognitive impairment, the person with Parkinson's disease often requires assistance in performing daily tasks. These can be grouped into instrumental activities of daily living (IADL; assistance with meal preparation, medication, housework, shopping etc.), and activities of daily living (ADL; dressing, walking and personal hygiene etc.; Landi et al., 2000; Morris, Fries, & Morris, 1999). Adapting to progressive loss of functional abilities is not only time consuming, it also disrupts routines and puts physical strain on carers (McLaughlin et al., 2011). Providing assistance with ADLs is resource intensive and physically demanding, but in contrast to providing ADL support to someone without dementia, carer psychological stress may be amplified in the context of dementia due to associated problems like resistance of care and short-term memory impairment. A number of meta-analyses and systematic reviews from the wider caregiving literature and Parkinson's disease specific literature, have found functional impairment to be predictive of caregiver stress (Lau & Au, 2011; Leiknes et al., 2015; Pinguart & Sørensen, 2007; Schrag et al., 2006; Viwattanakulvanid et al., 2014).

### **Neuropsychiatric symptoms.**

In those living with Parkinson's disease, neuropsychiatric symptoms have been found to be more pronounced than motor and functional status related symptoms (Martinez-Martin et al., 2015). Research provides consistent evidence that neuropsychiatric symptoms contribute to caregiver stress. (Aarsland et al., 1999; Greenwell et al., 2015; Leiknes et al., 2015; Mosley et al., 2017; Schrag et al., 2006; Viwattanakulvanid et al., 2014). With deteriorating cognitive function, many people living with dementia lose the ability to effectively communicate their intentions and needs, resulting in so called 'problem behaviours'. These include aggression in the form of hitting or verbal abuse; physically non-aggressive behaviours such as wandering or resisting care; and verbal agitation including screaming, complaining or repetitive remarks (Miller, Snowden & Vaughan, 1995). While these symptoms are more strongly associated with stress experienced by caregivers of clients with Alzheimer's disease, they also play a role for caregivers of clients with Parkinson's disease (Feast, Moniz-Cook, Stoner, Charlesworth, & Orrell, 2016; Thommessen et al., 2002).

Client depressive symptomology is perhaps the most robust and most frequently reported predictor of carer stress, but it is not unique to Parkinson's disease (Chiu, Tsai, Chen, Chen, & Lai, 2016; Lee et al., 2013; Mosley et al., 2017; Santos-García & de la Fuente-Fernández, 2015; Schrag et al., 2006; Shin et al., 2012; Viwattanakulvanid et al., 2014; Zhong et al., 2016). Depressive symptoms affect between 10-45% of clients with Parkinson's disease (Chaudhuri et al., 2006) and around 30% of carers (Happe & Berger, 2002). A client's lack of motivation, sadness, pessimism and suicidality can lead to greater dependence on and increased demands for support from their carer. Additionally, the interpersonal characteristics of a depressed person may limit the warmth and reciprocity within the caregiving dyad that often acts as a buffer for caregiver stress (Mosley et al., 2017).

Anxiety and depression frequently co-occur. Anxiety disorders are not unique to Parkinson's disease but when present, can include generalised anxiety disorder, panic

disorder, social phobia, fear of falling, as well as distress when the carer is out of sight.

Avoidance of triggers is the hallmark of all anxiety disorders, and while it primarily serves to maintain the disorder, it also contributes to caregiver burden. Fear of falling or concerns about others being able to see motor symptoms, curtails the dyad's social activities and can result in a reduction of social network, leading to caregivers' sense of being "prisoners in their own homes" (Mosley et al., 2017, pg. 225). Additionally, it may be draining if clients require constant reassurance from and presence of their caregiver. At present, evidence for the association between anxiety and carer stress is mixed (Lee et al., 2013; Szeto et al., 2016; Viwattanakulvanid et al., 2014; Zhong et al., 2016).

Another related and distinctive symptom of Parkinson's disease is apathy (Chaudhuri et al., 2006), which affects around 50% of patients (Jankovic, 2008). Within the context of decreased motivation and emotional expression, constant persuading and prompting to initiate tasks or participate in activities, can be draining for the caregiver (Mercer, 2015). Moreover, social interactions may lack warmth and humour, which effects the quality of caregiver dyad interactions (Mosley et al., 2017).

Sleep disruption, according to Chaudhuri et al. (2006), is a neuropsychiatric symptom that virtually all people living with Parkinson's disease suffer from, and that can be caused by a range of Parkinson's disease related symptoms such as pain, hallucinations and depression. This affects the primary caregiver independent of them sharing a bed, and is thought to be a risk factor for carer stress (Carod-Artal, Mesquita, Ziolkowski, & Martinez-Martin, 2013; Lee et al., 2013; Leiknes et al., 2015; Viwattanakulvanid et al., 2014) and caregiver depressive symptoms (Cupidi et al., 2013; Mosley et al., 2017). Approximately 27% of caretakers reportedly experience disturbance in their own sleep (Happe & Berger, 2002).

On the more severe spectrum of neuropsychiatric symptoms are psychotic symptoms, which are a distinguishing feature of Parkinson's disease. Psychosis includes hallucinations

and delusions, which occur in around 40% of patients with Parkinson's disease, and that have a tendency to get worse as the disease progresses (Chaudhuri et al., 2006). Hallucinations can be extremely distressing for the person with Parkinson's disease and their caregiver. When hallucinations occur during the night, the carer might additionally suffer from disturbed sleep. Delusions are fixed beliefs that can be especially distressing when the caregiver is incorporated into the delusional system, as in the case of delusional jealousy, in which the spouse is believed to be unfaithful and accused of infidelity (Mosley et al., 2017). There is consistent evidence that psychosis plays an important role in predicting stress in carers of clients with Parkinson's disease (D. Aarsland et al., 1999; Carod-Artal et al., 2013; Lee et al., 2013; Schrag et al., 2006). The negative effects of neuropsychiatric symptoms are plentiful. They may create feelings of shame and anxiety that prevent caregivers from accessing social support networks and clients to partake in social roles.

To summarise the effects of client characteristics on caregiver stress, client demographic characteristics appear to make a small and inconsistent contribution to caregiver stress. Client level of cognitive functioning, motor symptoms, falls and functional impairment have been fairly consistently related to caregiver stress, with motor symptoms being particularly relevant to clients with Parkinson's disease. As indicated by Parkinson's disease specific research, client neuropsychiatric compared to demographic, cognitive function and motor related symptoms, appear to have a larger impact on caregiver stress, with depression, psychosis and sleep disruption being particularly prominent in these clients.

### **Social integration**

Social support has been frequently studied in non-specific dementia caregiver populations and has been found to have a positive direct effect on caregiver wellbeing, as well as an indirect effect buffering against the negative aspects of caregiving (Greenwell et al., 2015). This appears to be influenced by client characteristics such as cognitive status,

which is associated with fewer social contacts and more loneliness in caregivers of clients with Alzheimer's disease (Kiecolt-Glaser et al., 1987). Most research has focused on caregiver psychosocial effects, rather than the effects of client psychosocial wellbeing. The sole effect of client social integration on caregiver stress seldom has been investigated, possibly due to caregiving usually occurring within a family context, which makes it difficult to isolate client or so called 'actor' effects. Social integration refers to the "entire set of an individual's connections to others in his or her environment and one's participation in meaningful roles" (Pillemer, 2000, p. 8). Birkel and Jones (1989) found that compared to families without the presence of dementia, families caring for a member with the disease, had a smaller social network, although this did not solely focus on the client.

One way by which this may occur is through fluctuating mood and disruptive behaviours associated with dementia, leading to caregivers' feelings of shame. Such feelings in turn may lead to subsequent isolation due to the tendency of older adults with dementia becoming increasingly housebound, thereby limiting their continued participation in social roles and their opportunities to connect with others. Similarly, older adults with physical disabilities compared to those, who additionally had dementia, tended to have larger overall networks and more helpers outside the home, which may reflect stigma around mental versus physical health issues. Theoretically, it seems plausible that when clients can still participate regularly in social activities and have support people around them, this may benefit the primary caregiver. For example, when the client is engaged in social activities the caregiver may have respite from care responsibilities. However, it is important to bare in mind that this may also place additional demands on caregivers to get their loved ones ready to go by a certain time in addition to logistical requirements. which can result in improved mood. Given this gap in the literature and the InterRAI-HC providing client focused data, such an investigation was possible.

## **Caregiver stress across levels of cognitive impairment and dementia subtype**

### **Parkinson's disease with (PDD) and without dementia (PD).**

There is consistent evidence for increasing carer stress as cognitive impairment progresses in clients with Parkinson's disease. Leroi et al. (2012) examined varying levels of cognitive functioning classified as no cognitive impairment (PD-NC), mild cognitive impairment (PD-MCI) and with dementia (PD-D), and their impact on caregiver burden. Their results showed that PD-D caregiver burden was significantly higher compared to caregivers of clients with PD-MCI (mild cognitive impairment) and PD-NC (normal cognition). However, there was no significant difference between carer stress levels of clients in the two non-dementia groups (PD-MCI and PD-NC), even after controlling for age and motor impairment severity. This suggests that cognitive impairment needs to be of sufficient magnitude to notably affect caregiver stress within a research context. A study by Jones et al. (2017) highlights the complexity of cognitive classification in clients with Parkinson's disease. By using a more refined neuropsychological testing battery than Leroi et al., they did find significant differences in caregiver stress across clients with PD-NC, PD-MCI and PD-D, suggesting that cognitive impairment has an impact on carer stress even when it is classified as mild.

A possible limitation of Leroi et al.'s study, was that they used a cumulative score of the Neuropsychiatric Inventory to assess the relationship between neuropsychiatric symptoms and carer stress. The authors found no significant difference between the three groups. On one hand, this may indicate that neuropsychiatric symptoms did not impact as much as cognitive impairment on disability and caregiver burden; however, this is unlikely, given the large amount of research suggesting a strong impact of neuropsychiatric symptoms on caregiver stress. On the other hand, the authors' null finding may have been attributable to them using a cumulative or total score when examining the effects of neuropsychiatric

symptoms. It is possible that using a cumulative score may have not been sensitive enough to detect the extent to which individual neuropsychiatric symptoms impacted on caregiver stress, thereby diluting potential findings (Leroi et al., 2012). It appears worthwhile to examine individual neuropsychiatric symptoms.

### **Dementia due to Parkinson's disease with (PD-D) and Alzheimer's disease (AD).**

Caregiver stress may not only vary by the degree of cognitive impairment but also by the underlying disease causing the dementia, i.e. Alzheimer's (AD) and Parkinson's disease. To date, few studies have examined this. There is a small amount of quantitative (Lee, McKeith, Mosimann, Ghosh-Nodyal, & Thomas, 2013; Shin et al., 2012; Svendsboe et al., 2016) and qualitative evidence (Roland & Chappell, 2017) implying that PD-D caregivers experience higher caregiver stress compared to AD caregivers. This conflicts with findings by Mitchell et al. (2015), who used an impressively large sample of Canadian home care clients. These were assessed by the International Resident Assessment Instrument (InterRAI-HC) to identify predictors of caregiver stress across multiple neurological conditions. Their sample included over 20,000 clients with Parkinson's disease and over 110,000 clients with Alzheimer's disease and related dementias. They found carers of clients with Alzheimer's and related dementia had higher odds of experiencing stress compared to carers of clients with Parkinson's disease after controlling for a range of known co-variables. Their predictors included client demographic and disease variables as well as caregiver characteristics. Notably, these researchers did not distinguish between level of cognitive impairment in clients with Parkinson's disease. By combining these distinct diagnostic client groups, the results were potentially diluted.

The evidence with regards to which caregiver stress predictors are differential for each diagnostic subgroup is inconclusive. Research suggests that, PD-D clients present with more daytime sleepiness, cognitive and behavioural fluctuations, and hallucinations than both AD

and PD clients (Scharre et al., 2016; Svendsboe et al., 2016). In addition to fewer memory problems and disorientation, PD-D clients have more executive function and visuospatial deficits compared to AD clients (Scharre et al., 2016). Executive function impairment reflects problems with decision making, distractibility, and visuospatial deficits, which could relate to falls and anticipatory anxiety of falls.

Similarly, Shin et al. (2012) found cognitive and ADL impairment to be predictive of AD carer stress, whereas memory problems, poor insight and volition, as well as hallucinations were predictive of PD-D carer stress. Client depression was predictive of carer stress in AD and PD-D groups. In contrast to this, a study by Lee et al., (2013) found that neuropsychiatric symptoms including depression, anxiety, apathy and delusions did not differ between AD and PD-D caregivers. The only exception was hallucinations, which were more stressful for PD-D caregivers. Yet another study found that for both AD and PD-D groups, sleep disorders, apathy and depression were the most commonly reported symptoms (Chiu et al., 2016). In total, the literature on these nuances is sparse and inconsistent, and there is an apparent gap in the literature regarding the extent to which caregiver stress in PD, PD-D and AD caregivers differs.

Overall, it seems that worse cognitive impairment is associated with more caregiver stress (i.e. PD-D vs PD). Sparse evidence supports the idea that different diseases underlying dementia have a differential effect on caregiver stress, as indicated by the few studies that have compared carers of clients with Alzheimer's disease and Parkinson's disease, although this is not conclusive. With regards to disease related predictors, it appears that client depression and functional impairment is predictive of both AD and PD-D carer stress, and hallucinations seem to have a greater impact on PD-D compared to AD carer stress.

## **Conclusion**

At present, there appear to be a number of limitations within the literature. Numerous researchers have attempted to establish a set of variables that are predictive of dementia caregiver stress; however, the literature is plagued by inconclusive evidence due to a range of factors. These include, being limited to using mediocre statistical analyses without controlling for established correlates due to small samples (Leiknes et al., 2015); treating dementia carers as a homogenous sample (Reviews: Feast, Moniz-Cook, Stoner, Charlesworth, & Orrell, 2016; Pinguart & Sørensen, 2003); looking at neurological disorders as a whole, which may dilute the effect of disorder specific predictors, such as in the case of Parkinson's disease with and without dementia (Mitchell et al., 2015; O'Connor & McCabe, 2011a); using cumulative rather than individual scores to assess neuropsychiatric, behavioural and cognitive symptoms (Black & Almeida, 2004; Feast et al., 2016); and using a variety of caregiver wellbeing indicators such as burden, mental health or quality of life as outcome variables.

Given the shortcomings of current research, the dataset which was used for the current study is able to address these in the following ways: Using a large sample of New Zealanders and their caregivers who are receiving home care; examining risk factors across neurological diseases and level of cognitive impairment by subdividing the sample into four groups, namely Parkinson's disease with and without dementia (PDD and PD), Alzheimer's and related dementias (AD+), and comparing these to a control group without any of these diseases (ND) but with significant health needs; using individual rather than cumulative scores of risk factors; and using an indicator of caregiver psychological health as a measure of caregiver stress.

## **Current study**

This study had four aims. The first aim was to describe the caregiver characteristics of home care clients across four diagnostic groups especially with regards to the magnitude of informal carer stress. It was predicted that caregiver stress was more prevalent in the PDD than all other diagnostic groups, followed by AD+, then PD and lastly ND. It was also predicted that spouses would experience more frequent caregiver stress compared to child or to other types of caregivers. In line with the literature we expected to find greater prevalence of carer stress in caregivers who provide longer hours of care and live together with the client.

The second aim included describing the client demographic, functional and neuropsychiatric characteristics across dementia types and levels of cognitive impairment. It was hypothesised that clients with PDD would be worse off compared to clients in PD, AD+ and ND groups in regards to cognitive fluctuation, activities of daily living, psychotic symptoms, sleep disturbances, and falls. Short-term memory impairment and problem behaviours were predicted to occur more frequently in the AD+ than PDD groups. In terms of client psychosocial characteristics it was predicted that a decline in social activities and loneliness was associated with caregiver stress, and presence of a second caregiver and more frequent social contact protected carers from experiencing stress.

The third aim was to investigate the importance of risk factors for caregiver stress, the study adapted analyses done by Mitchell et al. (2015) with a New Zealand sample to determine whether client diagnostic group predicts carer stress and the extent to which diagnostic group increases the odds for caregiver stress while controlling for known predictors. The 28 risk factors that will be included to predict caregiver stress are: Caregiver type, informal hours of care, co-habitation with the client, client age, gender, marital status, financial hardship, decision making problem, short-term memory problem, procedural

memory problem, disorganised speech, distractibility, cognitive fluctuation, wandering, verbal abuse, resisting care, falls, activities of daily living, instrumental activities of daily living, depression, abnormal thought, delusions, hallucinations, disturbed sleep, presence of a second caregiver, client loneliness, reduction in social activities, and frequency of social contact.

Lastly, to elucidate differential risk factors for caregiver distress unique to client diagnoses, the study will run individual analyses for each diagnostic group.

## **Method**

### **Study population**

The population used for this study consisted of older adults across New Zealand, who received an assessment using the International Residents Assessment Instrument – Home Care (InterRAI-HC) between September 2012 and January 2016; individuals included in this study gave consent for their anonymised data to be used for research purposes (Downes, Dever & Douglass as cited in Schluter et al., 2016). The New Zealand InterRAI-HC 9.1© version was used (InterRAI Corporation, Washington, D.C., 1994-2009; Appendix A); the New Zealand Ministry of Health owns the instrument's license and made it available for research.

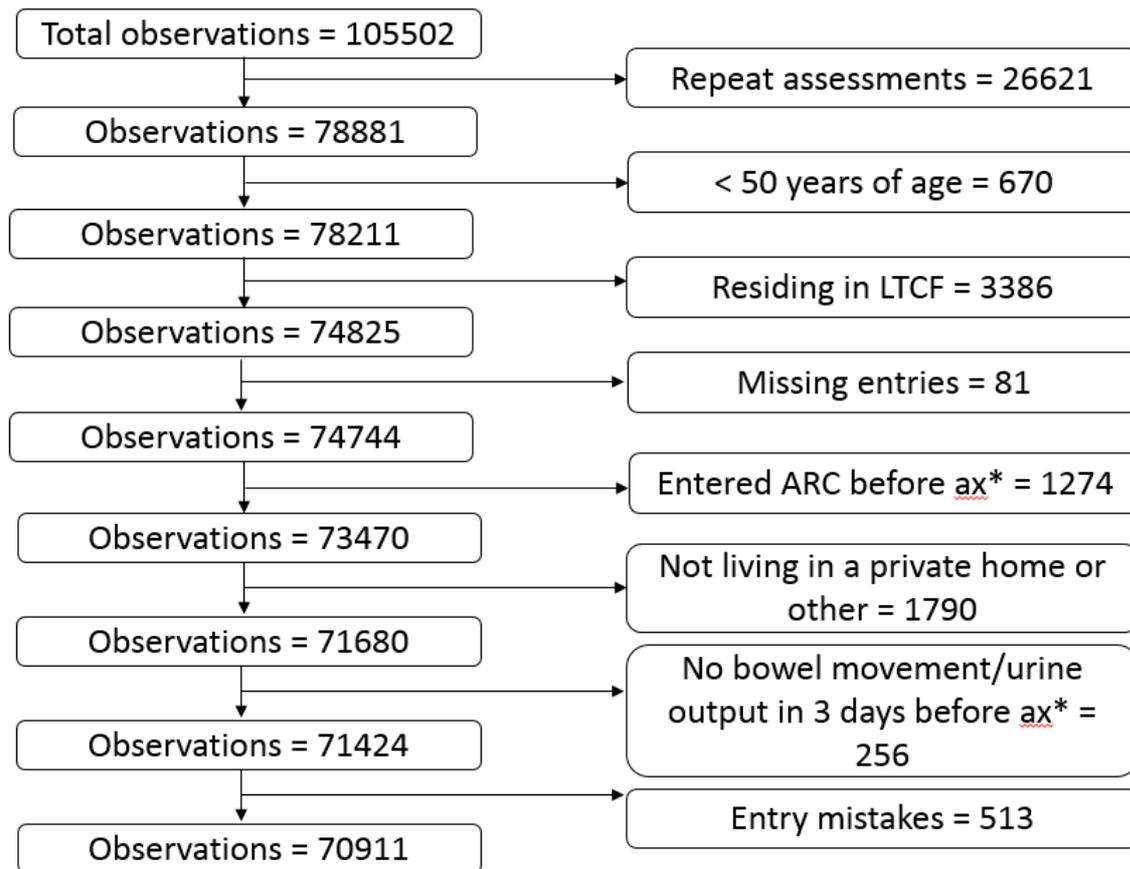
The initial sample included a total of 70,911 clients of which 6.5% ( $N = 4,645$ ) did not have a primary informal carer and were therefore excluded. This resulted in a final sample size of 66,266. The sample was divided into three neurological diagnostic categories and a control group as per the InterRAI Form items I1c, d, h (See Appendix A); the assessor determined this classification by reviewing health records and/ or the discharge summary or hospital electronic health records. The three diagnostic groups are Parkinson's disease without dementia (PD;  $N = 2,072$ ; 3%), Parkinson's disease with dementia (PDD;  $N = 534$ ;

0.8%), Alzheimer's disease or other dementia (AD+;  $N = 13,281$ ; 19.4%). The AD+ group predominantly includes clients with Alzheimer's disease, but also includes those who might have vascular, frontal lobe and Lewy body dementias. The remainder of the sample served as a comparison group consisting of clients who had none of the above diagnoses present (ND;  $N = 50,379$ ; 76.8%).

### **Data sources**

The original dataset underwent a number of logical coding checks and data cleaning procedures, which are summarised in Figure 1. This was a cross-sectional study, so any repeat assessments were excluded; that is, only the first assessment of each client was included. The focus on older clients with idiopathic Parkinson's disease led to the inclusion of clients over the age of 50 years and the exclusion of potential young-onset cases who were under the age of 50. Clients who were residing at a long-term care facility (LTCF) at the time of assessment were believed to either have received the wrong assessment or were artefacts of data entry errors and accordingly, were removed. Other exclusions were clients who entered aged residential care (ARC) between the referral and the assessment, those who were not living in either their private home, board and care, assisted living, group home for people with physical disability or setting for people with intellectual disability, and those who were reported as having no bowel movement or urine output in the three days prior to assessment.

Typically, a general practitioner, community health worker or hospital-based health professional identified and referred individuals requiring health care resources for an InterRAI-HC assessment. The aim of this process was to assist with individualised health-care plans, and identify support needs of older persons who are at risk of requiring long-term residential care (Perlman & Hirdes, 2008; Hirdes et al., 2008). Following the referral, a



\*ax = InterRAI-HC assessment

Figure 1. Data selection procedure.

trained clinical assessor, generally a nurse or social worker, phoned the individual or their family to arrange a visit in the person’s home. The assessment began with this initial phone call by noting aspects such as their hearing ability and the time it took for them to answer the phone.

During the home visit, observations such as the person’s ability to walk, making a cup of tea and visible physical symptoms were assessed. The personal interview guided by the InterRAI-HC form (Appendix A) constituted the bulk of the assessment and generally lasted about 45-60 minutes. While this procedure was the norm, there were occasions in which home care assessments occurred in the context of respite care or emergency situations. The goal was to complete the assessment within three days of the face-to-face visit. In order to fill out the InterRAI-HC form, assessors were required to use multiple sources of information in

addition to the personal interview, including direct observation, communication with the person's caregiver(s), review of medical records and the use of clinical communication between health care staff (Schluter et al., 2016). Assessors did not make a diagnosis of neurological diseases, as this was based on medical records.

## **Measures**

The InterRAI-HC contains 236 questions from which a total of 27 scales can be derived. The InterRAI-HC Assessment Form and User's Manual provided details regarding coding and examples for questioning strategies during assessment (Morris et al., 2009). For the purpose of this thesis, only the relevant items and scales with their respective psychometric properties are reviewed here. Specific items can be found on the InterRAI-HC form in Appendix A.

### **Caregiver stress.**

The primary informal helper was defined as the person who saw the client on a regular basis, responded to their needs and was viewed by the client as the most reliable and helpful carer. This informal helper could be a spouse or partner, family member, friend or neighbour and did not have to reside with the client (Morris et al., 2009, User's manual). The primary caregiver's psychological wellbeing, as an indicator of caregiver stress, was the key outcome variable in the current study and was assessed with one item that was coded dichotomously as follows: 'primary informal helper expresses feelings of distress, anger or depression' (InterRAI-HC form; P2b), coded as 1 = yes and 0 = No.

### **Caregiver Characteristics.**

#### ***Carer type.***

The relationship between primary caregiver and client was coded as 1 = child or child-in-law, 2 = spouse or partner, 3 = other, which included parents, guardians, siblings, other relatives or whānau, friends or neighbours (InterRAI-HC form; P1a).

***Co-habitation.***

Whether or not the primary caregiver lived with the client in the same household was coded as 0 = no and 1 = yes (InterRAI-HC form; P1b).

***Total Hours of informal care.***

‘Hours of informal care and active monitoring during the last three days’ was the item used to capture caregiver hours, and notably included help received from all the family, friends, neighbours and included, but was not limited to, care provided by the informal helper (InterRAI-HC form; P3). The variable ranged from 0-72 hours.

***Carer areas of help.***

Sections P1c and d on the InterRAI-HC form indicated if the primary carer was involved in assisting the client with IADLs and ADLs, respectively. The items were coded as 1 if the primary caregiver provided this.

***Client Characteristics.***

***Demographic characteristics.***

The clients’ demographic characteristics were described using the following items: Age (A3; continuous variable) and gender (A2) coded as 0 = female and 1 = male. Marital status (A4) was coded as 0 = not married and 1= married; married in this case include couples who are in a de facto relationship or civil union. Ethnicity (B2) was categorised into Maori, Pacific Island, European, Asian and other. Financial hardship (Q4) indicated whether or not clients had to make trade-offs among purchasing items such as food, shelter, clothing, prescribed medications and home heating or cooling in the last 30 days; this variable was coded as 0 = no and 1 = yes.

### ***Client Cognitive and Functional Status assessment.***

#### ***Cognition.***

The following InterRAI-HC items were used to assess cognition: Decision-making (C1), short-term memory (C2a) and procedural memory (C2b). The variable ‘decision making’ referred to the ability to make decisions regarding tasks of daily life such as when to get up or when to have meals, which clothes to wear or activities to do. It was coded as 0 = independent or modified independence and 1 = dependent. ‘Short-term memory’ was assessed as the ability to recall items or events after five minutes. ‘Procedural memory’ referred to the ability to perform all or almost all steps in a multitask sequence without cues. Both were coded as 0 = memory ok and 1 = memory problem. Morris et al. (1997) found good inter-reliability for ‘decision-making’ ( $K_w = 0.87$ ). Additional measures included ‘Easily distracted’, which described clients who experience episodes of difficulty paying attention or getting side-tracked (C3a); Daily cognitive fluctuations referred to clients’ mental function varying over the course of the day (C3c). Both items were coded as 0 = behaviour not present or behaviour consistent with usual functioning, in order to exclude potential non-dementia related symptoms stemming from pathologies such as ADHD, and 1 = behaviour present and different from usual functioning due to worsening or new onset.

#### ***Client functional status.***

The Activities of Daily Living Self-performance Hierarchy Scale (ADL Scale) was used to assess activities of daily living related to personal hygiene, locomotion and mobility, and eating over the past three days (Morris, Fries & Morris, 1999; Morris, Berg, Fries, Steel & Howard, 2013). The scale consisted of 10 items (InterRAI-HC Assessment form G2a-j). All items were scored on an 8-point scale ranging from 0 = independent (no physical assistance, set up or supervision required in any episode) to 6 = total dependence (full performance by others during all episodes), with higher scores indicating greater impairment in ADL

performance. If the activity did not occur in the previous three days it was coded as 8. The coding scheme determined the occurrence of an ADL during the specified time period, the types and frequency of assistance that was provided, the mix of physical support and self-performance. Landi et al. (2000) assessed the criterion validity for items relating to functional impairment, finding Pearson's correlation coefficients for MDS-ADL and The Barthel Activities of Daily Living Index to be 0.74. Another study found the scale to have good internal reliability ( $\alpha = 0.95$ ) across five countries and states (Morris, Carpenter, Berg, & Jones, 2000).

The Instrumental Activities of Daily Living Performance Scale (IADL scale) has eight items (meal preparation, ordinary housework, managing finances, medications, phone use, shopping, and transportation; G1a-h) and is coded the same way as the ADL Hierarchy Scale described above, to indicate the level of difficulty a client has performing these tasks. For example, meal preparation is described as 'how meals are prepared (e.g. planning meals, cooking, assembling ingredients, setting out food and utensils)' (Morris et al., 2009; appendix A). The scale ranged from 0-48 with higher scores indicating greater dependency. Landi et al. (2000) found the correlation between MDS-IADL and Lawton Index to be 0.81; Morris et al. (2000) found acceptable internal reliability ( $\alpha = 0.78$ ); and Morris et al. (1997) found the scale had good inter-rater reliability ( $K_w = 0.79$ ).

'Falls' were coded as 0 = no fall in the last 90 days and 1 = client fell within last 90 days (J1). Morris et al. (1907) found 'Behavioural symptoms' to have good inter-reliability ( $K_w = 0.72$ ).

### ***Client neuropsychiatric assessment.***

The 'Depression Rating Scale' (DRS) was used as a screening measure for depression (A. B. Burrows, Morris, & Simon, 2000) and is based on assessor observations and information provided by clients and carers. It consists of seven items (made negative statements;

persistent anger and irritability with self or others; expressions of what appears to be unrealistic fears; repetitive health complaints; repetitive anxious non-health-related complaints; sad facial expression; tearfulness; E1a-g) and was scored in regards to the frequency of expressed symptoms over a three-day period ranging from 0 = not present to 3 = exhibited daily. A score of three or above indicated the presence of minor or major depressive disorder and suggested a need for further evaluation of depressive symptoms. The original scale has been validated against the Hamilton Depression Rating Scale and the Cornell Scale for Depression in Dementia with correlations of 0.70 and 0.69 respectively and with a look-back period of 30 days for both scales. The depression rating scale was also found to have good sensitivity to detect depression in 91% of clients but low specificity (A. B. Burrows et al., 2000). However, a recent New Zealand based validation study tested the scale's validity with a three-day look-back period and found both diagnostic sensitivity and specificity to be poor with scores of 0.60 and 0.70 respectively. This New Zealand study suggests caution when using the scale to identify depression (Penny et al., 2016). Other psychiatric symptom variables included 'abnormal thought process' (loosening of associations, blocking, flight of ideas, tangentially; J3g), 'delusions' (fixed, false beliefs; J3h), 'hallucinations' (false sensory perceptions; J3i) and 'disturbed sleep'. The variable 'disturbed sleep' was re-coded for the logistic regression. It comprised both insomnia ('difficulty falling or staying asleep; waking up too early, restlessness or non-restful sleep'; J3o) and hypersomnolence items ('too much sleep that interferes with person's normal functioning'; J3p). All four psychiatric symptom variables were coded as 0 = not present and 1 = present (exhibited in last 3 days).

In addition, the behavioural symptoms wandering, verbal abuse and resisting care were coded as 0 = not present and 1 = symptom present. 'Wandering' described moving with no rational purpose and seemingly oblivious to needs or safety (E3a). 'Verbal abuse' included

threatening, screaming or cursing at others (E3b). ‘Resisting care’ involved resisting with administration of medications, injections, ADL assistance and eating (E3c).

### **Psychosocial assessment.**

Item F2 on the InterRAI-HC form assessed ‘loneliness’ in clients, whereby 1 = yes and 0 = no. ‘Change in social activities in the last 90 days’ was coded as 0 = no decline and 1 = decline (F3). The ‘social contact frequency’ variable was recoded from three InterRAI-HC form items namely ‘participation in social activities of long-standing interest’ (F1a); ‘visit with a long-standing social relation or family member’ (F1b); and ‘other interaction with long-standing social relation or family member e.g. telephone or email’ (F1c). These three categorical variables were summed up into a continuous variable ranging from 0 = never to 4 = within the last 3 days, with higher numbers indicating more frequent social contact.

### **Data Analysis**

The data were cleaned and checked for entry errors by Dr Shoorangiz, and Mr London provided the coding that enabled the analyses by diagnostic groups. The coding syntax can be found in Appendix B. In order to describe client demographic, functional and neuropsychiatric characteristics as well as carer characteristics across the four diagnostic groups, categorical variables were analysed using the customs table function in SPSS. Chi-square tests enabled testing for statistically significant differences between the proportions in each diagnostic group. For continuous variables such as age and hours of care, column proportions and ANOVAs determined statistically significant differences between diagnostic groups. The ‘compare column means’ function and Bonferroni method was selected for continuous variables to adjust p-values for multiple comparisons.

Next, the 28 risk factors were included in the logistic regression models. This selection was limited by the available data that was collected using the InterRAI-HC. The 28 risk

factors can be viewed in Table 6. To determine the extent to which diagnostic group increases the odds for caregiver stress, above and beyond known predictors, one binary logistic regression was run. This model included the 28 risk factors plus ‘diagnostic group’ as an additional set of predictors. To elucidate differential risk factors for caregiver distress unique to client diagnoses, four individual logistic regressions were run, one for each diagnostic group. All five regression models contained a total of 28 independent predictors, which were included hierarchically using blocks and only the final step in the analysis is presented in tables 6 and 7.

Block 1 included client and carer sociodemographic characteristics (client age, gender, marital status, financial hardship, carer type, informal care hours and co-habitation with the carer). Block 2 included client neuropsychiatric and functional variables (problem with decision-making, short-term and procedural memory, disorganised speech, distraction, cognitive fluctuations, wandering, verbal abuse, resisting care, falls, Activities of Daily Living Scale, Instrumental Activities of Daily Living Scale, Depression Rating Scale, abnormal thought, delusions, hallucinations and disturbed sleep). Block 3 contained client psychosocial variables (presence of a second carer, loneliness, change in client’s social activities in past 90 days and social contact frequency).

The Cox & Snell R Square and the Nagelkerke R Square values provide an indication of the amount of variance in caregiver stress the model can explain with each block. Rather than the R square values found in multiple regression, these are described as pseudo-R-square statistics. In consideration of the limitations of both statistics, values from both statistics (Cox & Snell R Square and Nagelkerke R Square) give a percentage range that suggests how much variability in caregiver stress is explained by a set of variables. The statistic R-square-change ( $\Delta R^2$ ) determines the additional variance the model can explain by adding another set of predictors. In order to calculate the  $\Delta R^2$  for each block, the pseudo-R-squares of a previous

block were subtracted from pseudo-R-squares of the next block. To illustrate with the PD group, if pseudo-R-squares ranged from 0.07-0.11 in block 1, they were subtracted from the pseudo-R-squares at block 2 (0.15-0.23) resulting in an  $\Delta R^2$  range of 0.08-0.12 or an additional variance of 8-12%.

## **Ethics**

The Ministry of Health's health and Disability Ethics Committee (14/STH/140) provided ethical clearance to use de-identified data from those who consented for their data to be used for research purposes.

## **Results**

### **Descriptive Statistics**

#### **InterRAI-HC caregiver characteristics.**

Table 1 presents carer characteristics including carer type, living status of the carer, hours of care provided in the last three days prior to the assessment, care activities and presence of carer distress, across the four diagnostic groups: Parkinson's disease without dementia (PD;  $N = 2,072$ ); Parkinson's disease with dementia (PDD;  $N = 534$ ); Alzheimer's disease and related dementias (AD+;  $N = 13,281$ ); and clients with none of these diagnoses (ND;  $N = 50,379$ ).

Clients in both Parkinson's disease groups were primarily cared for by their spouses, although clients with PDD had a higher proportion of spouses caring for them (PD = 53%; PDD = 70%). By contrast, over half of clients in the control group were cared for by their children or children-in-law. Clients in the AD+ group received care by equal proportions of child and spouse caregivers. Clients in the PDD group had the highest proportion of caregivers living with them (81%), followed by the PD group with 64%, and the AD+ group

with 62%. The control group had the smallest proportion of carers (43%) living with the client, which possibly reflects client marital status in this group (see Table 2).

In regards to the amount of time carers spent caregiving over the last three days prior to the InterRAI-HC assessment, carers of clients with PDD provided an average of 18 hours of care, which is significantly more care hours compared to all other groups. The least amount of hours caregiving occurred in the ND group (8 hours), followed by the PD (12 hours) and the AD+ group (15 hours). Over a course of three days, the PDD group also had the highest proportion of carers providing at least 22 hours of care, which is more than seven hours per day (PDD = 31%). This was followed by the AD+ group with 22%, then the PD group with 15% and ND group with 9%.

A higher proportion of PDD carers provided support with activities of daily living (69%) compared to all other groups, with the lowest in the ND group (PD = 52%; AD+ = 48%; ND = 32%). Across all groups, over 80% of carers provided help with instrumental activities of daily living and there was no significant difference between the three diagnostic groups (PD = 86%; PDD = 90%; AD+ = 87%), however the ND group was significantly lower (82%). The proportion of caregivers who expressed feelings of distress, anger or depression was significantly higher in the PDD group compared to all other groups (PDD = 36%), followed by the AD+ group (31%), then the PD group (21%). Caregiver stress was least prevalent in the ND group (15%).

Table 1. Carer characteristics.

		Diagnostic groups								$\chi^2/F$	<i>p</i>
		PD		PDD		AD+		ND			
		N( <i>M</i> )	%( <i>SD</i> )	N( <i>M</i> )	%( <i>SD</i> )	N( <i>M</i> )	%( <i>SD</i> )	N( <i>M</i> )	%( <i>SD</i> )		
Carer Type	Child or child-in-law	735 <sub>a</sub>	35.5%	139 <sub>b</sub>	26.0%	5960 <sub>c</sub>	44.9%	27523 <sub>d</sub>	54.6%	2171.6 <.001	
	Spouse or partner	1107 <sub>a</sub>	53.4%	376 <sub>b</sub>	70.4%	5847 <sub>c</sub>	44.0%	13959 <sub>d</sub>	27.7%		
	Other	230 <sub>a</sub>	11.1%	19 <sub>b</sub>	3.6%	1474 <sub>a</sub>	11.1%	8897 <sub>c</sub>	17.7%		
Lives with client		1324 <sub>a</sub>	63.9%	432 <sub>b</sub>	80.9%	8277 <sub>a</sub>	62.3%	21842 <sub>c</sub>	43.4%	1967.7 <.001	
CG hours		11.6 <sub>a</sub>	15.2	17.8 <sub>b</sub>	20.0	14.5 <sub>c</sub>	18.6	8.1 <sub>d</sub>	12.8	34.891 <.001	
CG hours groups	0-3h	770 <sub>a</sub>	37.2%	142 <sub>b</sub>	26.6%	4465 <sub>c</sub>	33.6%	25311 <sub>d</sub>	50.2%	2617.3 <.001	
	4-6h	316 <sub>a,b</sub>	15.3%	59 <sub>a</sub>	11.0%	1984 <sub>a</sub>	14.9%	8419 <sub>b</sub>	16.7%		
	7-9h	191 <sub>a</sub>	9.2%	50 <sub>a</sub>	9.4%	1082 <sub>a</sub>	8.1%	3865 <sub>a</sub>	7.7%		
	10-12h	213 <sub>a</sub>	10.3%	48 <sub>a,b</sub>	9.0%	1276 <sub>a</sub>	9.6%	4162 <sub>b</sub>	8.3%		
	13-15h	122 <sub>a</sub>	5.9%	33 <sub>a,b</sub>	6.2%	765 <sub>a</sub>	5.8%	2003 <sub>b</sub>	4.0%		
	16-18h	89 <sub>a</sub>	4.3%	18 <sub>a,b</sub>	3.4%	511 <sub>a</sub>	3.8%	1346 <sub>b</sub>	2.7%		
	19-21h	53 <sub>a</sub>	2.6%	18 <sub>a</sub>	3.4%	299 <sub>a</sub>	2.3%	709 <sub>b</sub>	1.4%		
22+h	318 <sub>a</sub>	15.3%	166 <sub>b</sub>	31.1%	2899 <sub>c</sub>	21.8%	4564 <sub>d</sub>	9.1%			
Carer helps with ADL		1075 <sub>a</sub>	51.9%	367 <sub>b</sub>	68.7%	6308 <sub>c</sub>	47.5%	16253 <sub>d</sub>	32.3%	251.3 <.001	
Carer helps with IADL		1773 <sub>a</sub>	85.6%	481 <sub>b</sub>	90.1%	11578 <sub>a,b</sub>	87.2%	41170 <sub>c</sub>	81.7%	1537.0 <.001	
CG distress		443 <sub>a</sub>	20.9%	193 <sub>b</sub>	36.1%	4048 <sub>c</sub>	30.5%	7448 <sub>d</sub>	14.8%	1859.3 <.001	

Note: Values in the same row not sharing the same subscript are significantly different at  $p < .05$  in the two-sided test of equality for column means. Tests are adjusted for all pairwise comparisons within a row using Bonferroni correction. *N* = sample size. *M* = mean. % = proportion of sample in group. *SD* = standard deviation.

### **InterRAI-HC client demographic characteristics.**

Table 2 presents client demographic characteristics age, sex, ethnicity, marital status and financial hardship across the four groups. The mean age across groups was similar (79-82 years). Clients in both Parkinson's disease groups were younger compared to clients in the AD+ and ND groups. Clients in the control group had the highest mean age. There were also significant differences when subdivided age distributions were used. That is, the age category 85+ contained a significantly higher proportion of clients in the ND group (42%), followed by the AD+ group (37%), whereas only about one fifth of clients in each Parkinson's group were 85 years or older. A large proportion of clients in PD, PDD and AD+ groups fell in the 75-84 age range (51%, 49%, 44%, respectively).

There was a higher proportion of female clients in the AD+ group (60%) and control group (63%) compared to both Parkinson's disease groups, which consisted of more male clients (PD = 58% and PDD = 69%). The ethnicity proportions varied significantly across the four groups. The PD group contained fewer Maori and Pacifica clients compared to other groups, and more Asians compared to the AD+ and ND group. There were fewer European New Zealanders in the AD+ group compared to other groups.

There were large group differences in marital status. A significantly higher proportion of clients in the Parkinson's disease groups were married (PD = 61%; PDD = 78%), whereas only 50% of AD+ clients and 37% of ND clients were married. Across groups, less than 3% of clients indicated that they had limited funds and had to make trade-offs when purchasing essential items in the last 30 days.

Table 2. InterRAI-HC client demographic characteristics.

		Diagnostic Groups								$\chi^2/F$	<i>p</i>
		PD		PDD		AD+		ND			
		N(M)	%(SD)	N(M)	%(SD)	N(M)	%(SD)	N(M)	%(SD)		
Age		79.5 <sub>a</sub>	7.1	79.1 <sub>a</sub>	7.1	81.7 <sub>b</sub>	7.9	82.2 <sub>c</sub>	8.6	1.02	0.05
Age by group	<65	49 <sub>a</sub>	2.4%	13 <sub>a,b</sub>	2.4%	445 <sub>a,b</sub>	3.4%	1855 <sub>b</sub>	3.7%	567.6	<.001
	65-74	474 <sub>a</sub>	22.9%	140 <sub>a</sub>	26.2%	1996 <sub>b</sub>	15.0%	8024 <sub>b</sub>	15.9%		
	75-84	1064 <sub>a</sub>	51.4%	260 <sub>a,b</sub>	48.7%	5899 <sub>b</sub>	44.4%	19219 <sub>c</sub>	38.1%		
	85+	485 <sub>a</sub>	23.4%	121 <sub>a</sub>	22.7%	4941 <sub>b</sub>	37.2%	21281 <sub>c</sub>	42.2%		
Gender	Male	1192 <sub>a</sub>	57.5%	368 <sub>b</sub>	68.9%	5413 <sub>c</sub>	40.8%	18619 <sub>d</sub>	37.0%	603.7	<.001
Ethnicity	Maori	44 <sub>a</sub>	2.1%	24 <sub>b</sub>	4.5%	877 <sub>b</sub>	6.6%	3079 <sub>b</sub>	6.1%	65.7	<.001
	Pacific Island	36 <sub>a</sub>	1.7%	15 <sub>a,b,c</sub>	2.8%	551 <sub>b</sub>	4.1%	1658 <sub>c</sub>	3.3%	42.4	<.001
	European	1901 <sub>a</sub>	91.7%	473 <sub>a,b,c</sub>	88.6%	11489 <sub>b</sub>	86.5%	44412 <sub>c</sub>	88.2%	56.5	<.001
	Asian	86 <sub>a</sub>	4.2%	19 <sub>a,b</sub>	3.6%	328 <sub>b</sub>	2.5%	1255 <sub>b,c</sub>	2.5%	24.6	<.001
	Other	22 <sub>a,b</sub>	1.1%	7 <sub>a,b</sub>	1.3%	151 <sub>a</sub>	1.1%	428 <sub>b</sub>	0.8%	11.0	<.001
Marital Status	Married <sup>1</sup>	1267 <sub>a</sub>	61.1%	415 <sub>b</sub>	77.7%	6681 <sub>c</sub>	50.3%	18577 <sub>d</sub>	36.9%	1475.7	<.001
Financial hardship		29 <sub>a</sub>	1.4%	9 <sub>a,b</sub>	1.7%	272 <sub>a</sub>	2.0%	1376 <sub>b</sub>	2.7%	32.8	<.001

Note: Values in the same row not sharing the same subscript are significantly different at  $p < .05$  in the two-sided test of equality for column means. Tests are adjusted for all pairwise comparisons within a row using Bonferroni correction. <sup>1</sup>Married includes de facto relationship or civil union.

### **InterRAI-HC client cognitive status, functional status and falls.**

Client cognitive and functional status, and falls, are presented in Table 3. As to be expected there was a significantly higher proportion of cognitive impairment present in clients of both dementia groups (PDD and AD+) compared to clients in the non-dementia groups (PD and ND) across all variables that assessed cognitive functioning. For example, over 90% of clients in the dementia groups had problems with short-term memory, with a slightly higher proportion in the AD+ group (90% in PDD vs 94% in AD+). In the ND and PD groups, 43% and 47%, respectively, had problems with short-term memory suggesting memory problems were frequent irrespective of group. Over three quarters of clients in both dementia groups had problems with daily decision-making and over 66% had problems with procedural memory. In terms of disorganised speech, easy distractibility and daily cognitive fluctuations, the pattern was similar; the proportions of clients in the dementia groups were higher compared to the non-dementia groups and there were no significant differences between the PDD and AD+ groups, and the ND and PD groups. Therefore, items relating to executive function associated with Parkinson's disease, were also impaired in clients with Alzheimer's and related dementias.

Clients in the PDD group required significantly more assistance with activities of daily living (ADL) compared to all other groups. There was no significant difference between proportions in PD and AD+ groups, and the control group required the least amount of assistance with ADLs. It is noteworthy to mention however, that the variances were very large, indicating large individual differences within the groups. Also, although the PDD group required the most assistance with ADLs, their score was still fairly low (2 out of a possible 6) indicating that on average, clients in the PDD group required limited assistance in one or more of the four ADLs (personal hygiene, toilet use, locomotion and eating).

Table 3. InterRAI-HC client cognitive status, functional status and falls.

	Diagnostic groups								$\chi^2/F$	p
	PD		PDD		AD+		ND			
	N(M)	%(SD)	N(M)	%(SD)	N(M)	%(SD)	N(M)	%(SD)		
Short-term Memory	972 <sub>a</sub>	46.9%	482 <sub>b</sub>	90.3%	12421 <sub>c</sub>	93.5%	21945 <sub>d</sub>	43.6%	10889.5	<.001
Decision Making	528 <sub>a</sub>	25.5%	418 <sub>b</sub>	78.3%	10212 <sub>b</sub>	76.9%	11081 <sub>c</sub>	22.0%	14745.2	<.001
Procedural Memory	404 <sub>a</sub>	19.5%	368 <sub>b</sub>	68.9%	8768 <sub>b</sub>	66.0%	8315 <sub>c</sub>	16.5%	13637.0	<.001
Disorganised Speech	34 <sub>a</sub>	1.6%	29 <sub>b</sub>	5.4%	530 <sub>b</sub>	4.0%	842 <sub>a</sub>	1.7%	296.5	<.001
Easily Distracted	41 <sub>a</sub>	2.0%	35 <sub>b</sub>	6.6%	759 <sub>b</sub>	5.7%	1278 <sub>a</sub>	2.5%	373.3	<.001
Cog. Fluctuations	62 <sub>a</sub>	3.0%	46 <sub>b</sub>	8.6%	838 <sub>b</sub>	6.3%	1554 <sub>a</sub>	3.1%	339.1	<.001
ADL Scale	1.3 <sub>a</sub>	1.6	2.0 <sub>b</sub>	1.7	1.2 <sub>a</sub>	1.4	0.9 <sub>d</sub>	1.5	272.0	<.001
IADL Scale	28.5 <sub>a</sub>	12.4	38.2 <sub>b</sub>	9.6	32.7 <sub>c</sub>	12.0	25.3 <sub>d</sub>	12.7	79.0	<.001
Fell within 90 days	1141 <sub>a</sub>	55.1%	325 <sub>a</sub>	60.9%	4874 <sub>b</sub>	36.7%	20474 <sub>c</sub>	40.6%	354.4	<.001

Note: Values in the same row not sharing the same subscript are significantly different at  $p < .05$  in the two-sided test of equality for column means. Tests are adjusted for all pairwise comparisons within a row using Bonferroni correction. ADL = Activities of daily living; IADL = Instrumental activities of daily living.

With regards to instrumental activities of daily living, clients in the PDD group scored an average of 38 (out of a possible 48). This was significantly higher than clients in the AD+ group ( $M = 32.7$ ,  $SD = 12.0$ ), PD group ( $M = 28.5$ ,  $SD = 12.4$ ) and the control group, which scored the lowest for IADL support with an average of 25 ( $SD = 12.7$ ). The control group's score nonetheless highlights the complex needs in this population. In terms of the prevalence of falls within the last 90 days of assessment, both Parkinson's disease groups were not significantly different from each other, and contained a significantly higher proportion of clients (PD = 55%; PDD = 62%) compared to the non-Parkinson's Disease groups. The control group had a significantly higher proportion of falls compared to the AD+ group (AD+ = 36.4%; ND = 40.2%).

### **InterRAI-HC client neuropsychiatric symptoms.**

The psychiatric symptoms are summarised in Table 4. In terms of mood symptoms, scores on the depression rating scale (DRS) were low across groups, indicating that, on average, none of the groups' scores fell within the depressive disorder range. A score of three or greater is suggested to be an indicator for the presence of a depressive disorder ( a B. Burrows, Morris, Simon, Hirdes, & Phillips, 2000; Penny et al., 2016). Both dementia groups (PDD and AD+) had higher ratings on the DRS compared to the non-dementia groups.

Clients in the PDD group had the highest proportion of clients experiencing abnormal thought process, delusions, and hallucinations (PDD = 12%, 15%, 31%, respectively) compared to all other groups. A significantly higher proportion of clients in the AD+ group experienced abnormal thought and delusions (8% and 9%, respectively) compared to clients in the PD group (3% for abnormal thought and delusions). In terms of hallucinations however, the PD group included a slightly higher proportion of clients (12%) compared to the AD+ group (10%). The control group contained the lowest proportion of clients with these symptoms, ranging from 2-3%.

Roughly one third of clients across diagnostic groups had sleep disturbance. The proportions of clients with disturbed sleep were significantly higher in both Parkinson's disease groups than non-Parkinson's groups, and there was no difference between the proportions in the PDD and PD group. Further, the control group (34%) contained a significantly higher proportion of clients with disturbed sleep than the AD+ group (29%, respectively). A significantly higher proportion of clients in the dementia groups compared to the non-dementia groups experienced wandering, verbal abuse as well as resistance during cares, and there were no significant differences between PDD and AD+ group proportions. The percentages of clients who experienced these problem behaviours ranged from 11-15% in the dementia groups and 1-4% in the non-dementia groups. These results show that

experiencing depressive symptomatology and problem behaviours (wandering, verbal abuse and resistance of care) were more prevalent in clients with dementia than clients without dementia, irrespective of dementia type; sleep disturbance was more common across Parkinson's than non-Parkinson's disease groups; and experiencing hallucinations was more common in the PDD group.

Table 4. InterRAI-HC client neuropsychiatric symptoms

	Diagnostic groups								$\chi^2/F$	<i>p</i>
	PD		PDD		AD+		ND			
	N(M)	%(SD)	N(M)	%(SD)	N(M)	%(SD)	N(M)	%(SD)		
DRS Scale	1.0 <sub>a</sub>	1.7	1.4 <sub>b</sub>	2.0	1.3 <sub>b</sub>	1.9	0.9 <sub>a</sub>	1.7	26.7	<.001
Abnormal Thought	55 <sub>a</sub>	2.7%	62 <sub>b</sub>	11.6%	1023 <sub>c</sub>	7.7%	908 <sub>d</sub>	1.8%	1353.2	<.001
Delusions	70 <sub>a</sub>	3.4%	78 <sub>b</sub>	14.6%	1243 <sub>c</sub>	9.4%	824 <sub>d</sub>	1.6%	2152.1	<.001
Hallucinations	244 <sub>a</sub>	11.8%	165 <sub>b</sub>	30.9%	1306 <sub>c</sub>	9.8%	1361 <sub>d</sub>	2.7%	2307.2	<.001
Disturbed Sleep	762 <sub>a</sub>	36.8%	209 <sub>a</sub>	39.1%	3818 <sub>b</sub>	28.7%	16923 <sub>c</sub>	33.6%	137.9	<.001
Wandering	40 <sub>a</sub>	1.9%	81 <sub>b</sub>	15.2%	1947 <sub>b</sub>	14.7%	615 <sub>c</sub>	1.2%	5080.4	<.001
Verbal Abuse	43 <sub>a</sub>	2.1%	61 <sub>b</sub>	11.4%	1819 <sub>b</sub>	13.7%	1280 <sub>a</sub>	2.5%	2928.3	<.001
Resists Care	64 <sub>a</sub>	3.1%	77 <sub>b</sub>	14.4%	1966 <sub>b</sub>	14.8%	1744 <sub>a</sub>	3.5%	2570.2	<.001

Note: Values in the same row not sharing the same subscript are significantly different at  $p < .05$  in the two-sided test of equality for column means. Tests are adjusted for all pairwise comparisons within a row using Bonferroni correction. DRS = Depression rating scale.

### InterRAI-HC client psychosocial characteristics.

Between 65-68% of clients had a second caregiver available and there were no differences between diagnostic groups (Table 5). Across groups, approximately 16-22% of clients felt lonely with the control group containing the highest proportion. In terms of decline in social activities over the last 90 days, the PDD group contained the highest proportion of clients (51%) compared to AD+ and ND groups (44% and 45%, respectively), which were not significantly different from each other. In line with this, clients in the PDD group were worse off when examining the frequency of social contact in the last month. Clients in the AD+ group had more frequent social contact than clients in the PDD group and

clients in the non-dementia groups had more frequent social contact compared to clients in both dementia groups.

Table 5. InterRAI-HC client psychosocial characteristics.

	Diagnostic groups								$\chi^2/F$	<i>p</i>
	PD		PDD		AD+		ND			
	N(M)	%(SD)	N(M)	%(SD)	N(M)	%(SD)	N(M)	%(SD)		
Second Carer	1348 <sub>a</sub>	65.1%	348 <sub>a</sub>	65.2%	8996 <sub>a</sub>	67.7%	33546 <sub>a</sub>	66.6%	9.7	< .05
Lonely	424 <sub>a,c</sub>	20.5%	87 <sub>a,b</sub>	16.3%	2379 <sub>b</sub>	17.9%	11038 <sub>c</sub>	21.9%	108.9	<.001
↓ social activities	935 <sub>a,b</sub>	45.1%	273 <sub>a</sub>	51.1%	5828 <sub>b</sub>	43.9%	22651 <sub>b,c</sub>	45.0%	13.8	<.01
Social contact frequency	8.7 <sub>a</sub>	2.8	7.9 <sub>b</sub>	2.98	8.3 <sub>c</sub>	2.9	8.9 <sub>a</sub>	9.7	77.6	< .001

Note: Values in the same row not sharing the same subscript are significantly different at  $p < .05$  in the two-sided test of equality for column means. Tests are adjusted for all pairwise comparisons within a row using Bonferroni correction.

### Overview of Logistic regression analyses

A total of five binary logistic regressions were performed using 28 risk factors to assess their relative strength associated with caregiver stress; that is, the likelihood that caregivers were rated as expressing feelings of distress, anger or depression. Additionally, logistic regressions were able to assess the extent to which the regression models were able to distinguish between caregivers who were rated as experiencing carer stress and those who were not. The 28 risk factors that were included in the logistic regression models can be seen in Table 6). The first binary logistic regression was run to determine the extent to which diagnostic group increased the odds for caregiver stress, above and beyond known predictors. This first model is referred to below as a ‘combined logistic regression model’, the results of which are shown in Table 6 and includes the entire sample. In addition to the 28 predictors a ‘diagnostic group’ variable was used as a further predictor variable to ascertain whether diagnosis per se is predictable of carer stress.

The four remaining logistic regressions were run to elucidate differential risk factors for caregiver distress across different diagnoses and are referred to below as ‘individual logistic regression models’. Table 7 summarises the last step of the four hierarchical regressions for each diagnostic group showing odds ratios and confidence intervals. Tables C1-C4 in appendix C show regression coefficients, Wald statistics, odds ratios, and 95% confidence intervals for odds ratios for each of the four regressions.

### **Combined logistic regression model**

The combined logistic regression model refers to the entire sample and includes the diagnostic groups as a predictor variable added in the last step of the analysis. The full model containing all predictors was statistically significant ( $\chi^2(32, N = 65856) = 9062.3, p < .001$ ). This indicates that the model was able to distinguish between caregivers who were rated as experiencing carer stress and those who were not. Overall, the model explained between 13-21% of variance in caregiver stress using pseudo-R-squares Cox & Snell as well as Nagelkerke. Classification accuracy was acceptable with the model being able to accurately classify 83% of carers, who were rated as experiencing stress and those who were not. Table 6 shows regression coefficients, Wald statistics, odds ratios, and 95% confidence intervals for odds ratios.

The 28 risk factors plus diagnostic group as an additional predictor were added hierarchically in four blocks: First, client and carer sociodemographic characteristics; second, client neuropsychiatric and functional variables; third client psychosocial variables; lastly, diagnostic groups. Each added block explained a significant amount of variance. The risk factors included in block 2 explained an additional variance ranging from 7-20%; the addition of psychosocial variables in block 3 only explained 1% of extra variance in caregiver stress; adding the diagnostic group variables as a predictor in the last step explained an extra amount of variance, albeit very small (< 1%). Carers of clients with Alzheimer’s or related dementias

had a significant odds ratio of 1.14, which means that caregivers in this group have slightly higher odds of experiencing stress compared to caregivers of clients in Parkinson's disease or control groups. It also appears that client diagnosis per se does not have a major impact above and beyond known risk factors.

With regards to client sociodemographic predictors, the odds of caregiver stress increased by 1.4 with presence of financial hardship; 1.3 as a carer of a male client; and 1.2 when married. In terms of caregiver type, the odds of carer stress decreased by 37% when the carer was a parent, sibling, other whānau, friend, neighbour, or guardian. Living in the same household as the client had a 1.6 increase in the odds of experiencing caregiver stress. Providing longer hours of care, increased the odds of caregiver stress minimally. Regarding neuropsychiatric symptoms and functional status, carers of clients who had problems making decisions and were verbally abusive had the highest odds of experiencing caregiver stress (OR = 1.6 and 1.9, respectively). Additionally, resisting care, falls, client depression, delusions and disturbed sleep increased the likelihood of caregiver stress. Having a second carer present and having social contact decreased the odds of carer stress slightly (by 14% and 3%, respectively). Client loneliness and change in social activities in the last 90 days increased the odds of caregivers experiencing stress by 18% and 14% respectively.

### **Individual logistic regression models**

The individual models refer to separate logistic regressions that were run for each group (PD, PDD, AD+ and ND; see Table 7). The logistic regression models for all four diagnostic groups containing all 28 risk factors were statistically significant; PD:  $\chi^2(29, N = 2061) = 336.9, p < .001$ ; PDD:  $\chi^2(29, N = 526) = 78.0, p < .001$ ; AD+:  $\chi^2(29, N = 13159) = 1727.7, p < .001$ ; ND:  $\chi^2(29, N = 50110) = 5540.3, p < .001$ . Classification accuracy was acceptable; the models were able to accurately classify between 71-86% of carers, who were rated as experiencing stress and those who were not. The models were able to explain between 11-

24% of variance in caregiver stress (Cox & Snell and Nagelkerke  $R^2$ ), whereby the greatest variance was explained in the PD group (Cox and Snell:  $R^2_{PD} = .15$ ;  $R^2_{PDD} = .14$ ;  $R^2_{AD+} = .12$ ;  $R^2_{ND} = .11$ ; Nagelkerke:  $R^2_{PD} = .24$ ;  $R^2_{PDD} = .19$ ;  $R^2_{AD+} = .17$ ;  $R^2_{ND} = .19$ ).

Table 7 presents the odds ratios and their 95% confidence intervals of the last step of the logistic regressions for each of the 28 predictors in each diagnostic group as well as R-square-change ( $\Delta R^2$ ). Similar to the combined logistic regression model described above, the risk factors for the four individual logistic regression models were added hierarchically in three blocks: First, client and carer sociodemographic characteristics; second, client neuropsychiatric and functional variables and lastly client psychosocial variables. For all diagnostic groups, each added block explained a significant amount of variance. The predictors included in block 2 explained an additional variance ranging from 5-12%; the addition of psychosocial variables in block 3 explained a minimal amount (1-2%) of extra variance in caregiver stress. The following reports overall findings for each diagnostic group and then focuses on key results in sociodemographic, functional, neuropsychiatric and psychosocial domains.

For caregivers in the PD group, there was almost twice the chance of experiencing stress if they lived with the client than not. Stress further increased when the client had problems making decisions, had signs of depression, presence of hallucinations, disturbed sleep, experienced a decrease in social activities, and decreased odds of stress when a second caregiver was present. In comparison, caregivers of clients with PDD had a high likelihood of experiencing stress, if the client had short-term memory problems and displayed wandering behaviour. Again, the chance of carer stress was reduced when there was a second caregiver present. Caregivers in the AD+ group had higher odds of caregiver stress if they lived with the client and if the client was male. The chance of carer stress was lower when caregivers were children or children in law, siblings, extended whānau, neighbours, and friends. Stress

for caregivers further increased in the context of client decision making problems, procedural memory problems, wandering behaviour, verbal abuse, resistance of care, falls, signs of depression, abnormal thought, delusions, disturbed sleep, loneliness and decrease in social activities. Only caregivers in the AD+ did not benefit from the presence of a second carer but benefitted slightly if the client had more social contact.

The control group had the largest sample size and the highest number of significant odds ratios. Caregivers in the control group had an increased chance of being classified as experiencing stress when the client was male, married and the caregiver lived with them. Financial hardship increased the likelihood of carer stress only in the control group. Caregivers who were siblings, extended whānau, friends or neighbours were less likely to experience stress. Caregiver stress in the control group was further increased when the client had problems making decisions, displayed verbal abuse, resisted care, experienced falls, had signs of depression, presence of delusions and disturbed sleep. In regards to psychosocial factors, the likelihood of caregiver stress decreased in the presence of a second caregiver and if clients had social contact, but increased slightly if clients were lonely or had to limit their social activities.

In terms of sociodemographic predictors, looking after a male client was a significant risk factor for caregiver stress in the AD+ and ND groups (OR = 1.34 and 1.27 respectively) but less so for the two Parkinson's disease groups. Financial hardship was a significant predictor only in the ND group, making carers in this group 1.5 times more likely to experience caregiver stress. Compared to being a spousal caregiver, being a child or child-in-law caregiver, decreased the odds of caregiver stress only in the AD+ group (OR = 0.83). Caregivers who were other relatives or friends had a decreased likelihood of carer stress in the AD+ and ND groups (AD+: OR = 0.57; ND: OR = 0.61). Co-habitation increased the odds of carer stress 1.5 – 1.9 times for carers in the PD, AD+ and ND groups, with carers in

the PD group being at the highest risk. The odds ratio for the PDD group was not significant (OR = 1.83), possibly indicating a power problem in this group. Overall, living with the client showed to have the largest negative impact on carer stress across groups.

With regards to cognitive and psychiatric predictors, verbal abuse and decision making difficulties were among the highest significant predictors in the AD+ and ND groups; carers who experienced verbal abuse from their loved ones were 1.7 and 2.3 times more likely to experience carer stress respectively; problems with decision making increased odds of carer stress in PD, AD+ and ND groups 1.7, 1.6 and 1.6 times, respectively. The odds ratio (OR = 1.5) in the PDD group was not statistically significant. Short-term memory problems increased carer stress 2.8 and 1.2 times in PDD and ND carers, respectively. Wandering was a significant predictor for carer stress in both dementia groups, however with higher odds in the PDD group (OR = 1.8) compared to the AD+ group (OR = 1.1). Hallucinations increased odds of carer stress 1.4 times albeit only in the PD group. Disturbed sleep increased the odds of carer stress 1.2-1.3 times in PD, AD+ and ND groups. The odds ratio in the PDD group was not significant (OR = 1.20).

In terms of psychosocial predictors, the presence of a second caregiver in addition to the primary carer decreased the odds of carer stress across all groups except the AD+ group, with the greatest impact seen in the PDD group, in which the odds of carer stress decreased by 35%. Client loneliness increased carer stress in the AD+ and ND groups. Caregivers of clients who experienced a decline in social activities over the last 90 days had increased odds of experiencing carer stress in PD, AD+ and ND groups (OR = 1.3; OR = 1.2; OR = 1.1, respectively). The odds of caregiver stress in AD+ and ND groups decreased between 3-4% when clients had more social contact. Tables C1-C4 in appendix C show regression coefficients, Wald statistics, odds ratios, and 95% confidence intervals for odds ratios for the last step of each of the four regressions.

Table 6. Combined logistic regression

	B	S.E.	Wald	df	p	Odds ratio	95% CI	
							Lower	Upper
<b>Block 1</b>								
Client age	0.00	0.00	7.83	1	0.01	1.00	0.99	1.00
Male client	0.26	0.02	120.74	1	0.00	1.30	1.24	1.36
Married	0.15	0.04	15.35	1	0.00	1.17	1.08	1.26
Financial hardship	0.31	0.06	22.71	1	0.00	1.36	1.20	1.54
Carer type (Spouse=ref)			143.83	2	0.00			
Children <sup>1</sup>	0.07	0.04	2.48	1	0.12	1.07	0.98	1.17
Other	-0.47	0.04	137.41	1	0.00	0.63	0.58	0.68
Informal care hours in 3 days	0.01	0.00	185.26	1	0.00	1.01	1.01	1.01
Lives with client	0.49	0.03	231.65	1	0.00	1.63	1.53	1.74
<b>Block 2</b>								
Decision making problem	0.45	0.03	217.86	1	0.00	1.57	1.48	1.66
Short-term memory problem	0.22	0.03	59.20	1	0.00	1.24	1.18	1.32
Procedural memory problem	0.04	0.03	1.77	1	0.18	1.04	0.98	1.10
Disorganised speech	-0.06	0.08	0.57	1	0.45	0.94	0.81	1.10
Easily distracted	0.01	0.07	0.02	1	0.89	1.01	0.88	1.15
Daily cognitive fluctuations	0.05	0.06	0.73	1	0.39	1.05	0.93	1.19
Wandering	0.08	0.05	2.82	1	0.09	1.09	0.99	1.19
Verbal abuse	0.63	0.04	202.86	1	0.00	1.87	1.72	2.04
Resists care	0.26	0.04	38.42	1	0.00	1.30	1.19	1.41
Falls	0.17	0.02	53.68	1	0.00	1.18	1.13	1.24
ADL	-0.03	0.01	9.36	1	0.00	0.97	0.96	0.99
IADL	0.02	0.00	159.90	1	0.00	1.02	1.01	1.02
DRS	0.17	0.01	792.89	1	0.00	1.18	1.17	1.20
Abnormal thought	0.07	0.06	1.39	1	0.24	1.07	0.96	1.20
Delusions	0.26	0.06	20.98	1	0.00	1.29	1.16	1.44

Table 6. Cont.

	B	S.E.	Wald	df	p	Odds ratio	95% CI	
							Lower	Upper
Hallucinations	-0.04	0.05	0.80	1	0.37	0.96	0.87	1.05
Disturbed sleep	0.18	0.02	57.30	1	0.00	1.19	1.14	1.25
<b>Block 3</b>								
Second carer present	-0.15	0.02	40.69	1	0.00	0.86	0.82	0.90
Lonely	0.17	0.03	36.50	1	0.00	1.19	1.12	1.26
↓ social activities	0.14	0.02	36.85	1	0.00	1.15	1.10	1.20
Social contact frequency	-0.03	0.00	44.95	1	0.00	0.97	0.96	0.98
<b>Block 4</b>								
Diagnostic groups			21.97	3	0.00			
AD+	0.14	0.03	20.64	1	0.00	1.15	1.08	1.22
PD	0.08	0.06	1.84	1	0.17	1.09	0.96	1.22
PDD	0.00	0.10	0.00	1	0.96	1.00	0.82	1.21

Note: <sup>1</sup> Children includes children-in-law. DRS = Depression rating scale.

Table 7. Odds ratios and confidence intervals for predicting carer stress in PD, PDD, AD+ and ND groups. Note: This table presents the results of a total of four logistic regressions.

	PD	95% CI		PDD	95 % CI		AD+	95% CI		ND	95 % CI		
<b>Block 1</b>													
R <sup>2</sup>		0.07-0.11				0.06-0.08			0.05-0.07			0.05-0.09	
Client age	0.99	0.97	1.01	1.02	0.99	1.05	<b>0.99</b>	<b>0.99</b>	<b>1.00</b>	1.00	1.00	1.00	1.00
Male client	1.30	1.00	1.68	0.98	0.60	1.60	<b>1.34</b>	<b>1.23</b>	<b>1.46</b>	<b>1.27</b>	<b>1.20</b>	<b>1.34</b>	<b>1.34</b>
Married	1.44	0.90	2.32	1.68	0.68	4.14	1.00	0.85	1.17	<b>1.25</b>	<b>1.14</b>	<b>1.36</b>	<b>1.36</b>
Financial hardship	1.15	0.48	2.77	0.54	0.09	3.18	1.19	0.91	1.57	<b>1.45</b>	<b>1.26</b>	<b>1.68</b>	<b>1.68</b>
Carer type (Spouse=ref)													
Children <sup>1</sup>	0.91	0.55	1.50	0.83	0.35	2.02	<b>0.83</b>	<b>0.70</b>	<b>0.98</b>	1.00	0.90	1.10	1.10
Other	0.93	0.47	1.84	0.37	0.06	2.16	<b>0.57</b>	<b>0.46</b>	<b>0.71</b>	<b>0.61</b>	<b>0.53</b>	<b>0.69</b>	<b>0.69</b>
Informal care hours in 3 days	<b>1.01</b>	<b>1.00</b>	<b>1.02</b>	1.01	1.00	1.02	<b>1.01</b>	<b>1.00</b>	<b>1.01</b>	<b>1.01</b>	<b>1.01</b>	<b>1.01</b>	<b>1.01</b>
Lives with client	<b>1.92</b>	<b>1.26</b>	<b>2.93</b>	1.83	0.78	4.27	<b>1.50</b>	<b>1.33</b>	<b>1.69</b>	<b>1.68</b>	<b>1.55</b>	<b>1.81</b>	<b>1.81</b>
<b>Block 2</b>													
R <sup>2</sup>		0.15-0.23				0.13-0.17			0.12-0.17			0.10-0.18	
ΔR <sup>2</sup>		0.08-0.12				0.07-0.09			0.07-0.10			0.05-0.09	
Decision making problem	<b>1.66</b>	<b>1.23</b>	<b>2.25</b>	1.52	0.83	2.80	<b>1.63</b>	<b>1.45</b>	<b>1.84</b>	<b>1.57</b>	<b>1.46</b>	<b>1.68</b>	<b>1.68</b>
Short-term memory problem	1.17	0.90	1.54	<b>2.88</b>	<b>1.25</b>	<b>6.65</b>	1.08	0.90	1.29	1.22	1.15	1.30	1.30
Procedural memory problem	0.97	0.70	1.35	0.81	0.48	1.35	<b>1.19</b>	<b>1.07</b>	<b>1.31</b>	1.01	0.94	1.09	1.09
Disorganised speech	0.83	0.32	2.17	2.65	0.56	12.59	1.16	0.90	1.49	0.83	0.67	1.02	1.02
Easily distracted	0.76	0.32	1.81	0.30	0.07	1.37	1.20	0.96	1.49	0.94	0.79	1.12	1.12
Daily cognitive fluctuations	1.32	0.67	2.59	0.85	0.35	2.02	0.91	0.74	1.11	1.12	0.96	1.31	1.31
Wandering	1.26	0.62	2.60	<b>1.81</b>	1.02	3.22	<b>1.14</b>	<b>1.01</b>	<b>1.27</b>	1.16	0.96	1.41	1.41
Verbal abuse	1.32	0.63	2.74	1.26	0.65	2.43	<b>1.65</b>	<b>1.47</b>	<b>1.86</b>	<b>2.28</b>	<b>2.00</b>	<b>2.60</b>	<b>2.60</b>
Resists care	1.26	0.69	2.30	1.03	0.57	1.86	<b>1.34</b>	<b>1.20</b>	<b>1.51</b>	<b>1.33</b>	<b>1.18</b>	<b>1.50</b>	<b>1.50</b>

Table 7. Cont.

	PD	95% CI		PDD	95 % CI		AD+	95% CI		ND	95 % CI	
Falls	1.27	0.99	1.62	1.44	0.95	2.16	<b>1.19</b>	<b>1.10</b>	<b>1.30</b>	<b>1.18</b>	<b>1.11</b>	<b>1.24</b>
ADL	1.09	0.99	1.19	1.03	0.88	1.20	<b>0.93</b>	<b>0.89</b>	<b>0.96</b>	0.98	0.96	1.00
IADL	1.01	1.00	1.03	0.99	0.96	1.02	1.00	0.99	1.00	<b>1.02</b>	<b>1.02</b>	<b>1.03</b>
DRS	<b>1.21</b>	1.13	1.30	1.11	1.00	1.24	<b>1.16</b>	<b>1.13</b>	<b>1.19</b>	<b>1.19</b>	<b>1.17</b>	<b>1.21</b>
Abnormal thought	1.19	0.61	2.31	1.05	0.53	2.07	<b>1.17</b>	<b>1.01</b>	<b>1.37</b>	0.94	0.79	1.13
Delusions	0.94	0.52	1.70	1.00	0.53	1.91	<b>1.30</b>	<b>1.13</b>	<b>1.51</b>	<b>1.26</b>	<b>1.05</b>	<b>1.51</b>
Hallucinations	<b>1.42</b>	<b>1.01</b>	<b>2.00</b>	1.10	0.71	1.70	0.97	0.84	1.11	0.89	0.77	1.03
Disturbed sleep	<b>1.32</b>	<b>1.03</b>	<b>1.68</b>	1.20	0.80	1.81	<b>1.31</b>	<b>1.20</b>	<b>1.43</b>	<b>1.17</b>	<b>1.10</b>	<b>1.23</b>
<b>Block 3</b>												
R <sup>2</sup>		0.15-0.24			0.14-0.19			0.12-0.17			0.11-0.19	
ΔR <sup>2</sup>		0.00-0.01			0.01-0.02			0.00			0.01	
Second carer present	<b>0.74</b>	<b>0.58</b>	<b>0.95</b>	<b>0.65</b>	<b>0.43</b>	<b>0.99</b>	0.89	0.81	0.97	<b>0.86</b>	<b>0.81</b>	<b>0.91</b>
Lonely	1.12	0.82	1.53	1.05	0.60	1.83	<b>1.17</b>	<b>1.05</b>	<b>1.31</b>	<b>1.19</b>	<b>1.11</b>	<b>1.27</b>
↓ social activities	<b>1.35</b>	<b>1.06</b>	<b>1.72</b>	1.07	0.72	1.60	<b>1.16</b>	<b>1.07</b>	<b>1.26</b>	<b>1.12</b>	<b>1.06</b>	<b>1.18</b>
Social contact frequency	0.97	0.93	1.02	0.94	0.88	1.01	<b>0.97</b>	<b>0.95</b>	<b>0.98</b>	<b>0.97</b>	<b>0.96</b>	<b>0.98</b>

Note: Significant odds ratios ( $p < .05$ ) are bold. R<sup>2</sup> states a range of two indices (Cox & Snell and Nagelkerke). <sup>1</sup> Children includes children-in-law. DRS = Depression rating scale.

## **Discussion**

The study aimed to describe caregiver and client characteristics as well as predictors of carer stress across four diagnostic groups in a large sample of community-dwelling New Zealanders with significant health needs. The large study population permitted differentiation between caregivers of clients with Parkinson's disease with (PDD) and without dementia (PD), clients living with Alzheimer's disease and related dementias (AD+), and those clients without any of the above mentioned diseases (ND). The study had several aims: First, to describe and compare caregiver characteristics of each diagnostic group, and to examine the association between those characteristics and carer stress. Second, to examine client characteristics, including client social integration in relation to caregiver stress. Third, to examine whether there is a difference in prevalence of caregiver stress between diagnostic groups and to examine whether this difference remains once client and caregiver characteristics were controlled for. Fourth, to explore whether unique risk factors for caregiver stress emerge for each diagnostic group when the groups were analysed separately.

### **Caregiver characteristics**

Caregiver characteristics varied significantly across groups. The majority of clients in both Parkinson's disease groups were cared for by their spouse. Spousal caregivers were less prevalent in the AD+ group and least prevalent in the ND group. Conversely, children or children-in-law were more prevalent caregivers in the ND group, followed by the AD+ group, with both Parkinson's disease groups having a lower prevalence of child caregivers. Unlike previous research (Pinquart & Sörensen, 2003; Viwattanakulvanid et al., 2014), the current study did not show that spousal caregivers were at higher risk of caregiver stress compared to children or children-in-law. To our knowledge, due to small sample sizes, previous research has rarely

been able to include as predictor variables carers who were siblings, other whānau, guardians, friends or neighbours and this study found this group to be at lower risk of experiencing stress compared to spousal and child caregivers (Greenwell et al., 2015; Mitchell et al., 2015; O'Connor & McCabe, 2011b; Zhong et al., 2016). It should be noted that when caregiver characteristics were analysed as predictors of carer stress for each group separately, the difference between spouses and other caregivers was only significant in the AD+ and ND group. This may be due to the smaller sample size (hence a power problem) of both PD groups compared to the AD+ and ND groups.

The vast majority (80%) of clients in the PDD group were living with their caregiver, followed by around 65% of the clients in the PD and AD+ groups, and less than half (43%) of clients in the ND group. Co-habitation has been found to be an inconsistent risk factor for carer distress in the literature (Greenwell et al., 2015; Pinqart & Sörensen, 2003; Shin et al., 2012), and findings from the current study suggest that it predicts caregiver stress. It further appeared that it is especially stressful for caregivers of clients with PD.

Caregivers of both dementia groups provided more hours of care compared to caregivers in the non-dementia groups. The finding that carers who provide longer hours of care have higher odds of experiencing carer stress, compared to caregivers who provide less hours of care, is consistent with previous findings (Greenwell et al., 2015; Zhong et al., 2016). However, the magnitude of the relationship between hours of care and caregiver stress was small, which may be explained by the fact that the variable 'hours of care' was rated with regards to all available caregivers and did not uniquely relate to the primary caregiver. A higher proportion of caregivers in the PDD group provided support with ADLs, compared to all other groups. However, neither support with ADLs nor IADLs were substantially related to caregiver stress. This is in contrast to

findings from a meta-analysis that found motor symptoms and ADL dependency to be among the highest correlates with caregiver stress (Lau & Au, 2011). It is possible that the physical nature of supporting clients with their ADLs and IADLs may not be reflected in the outcome measure, which relates more to psychological stress.

### **Caregiver stress**

On a univariate level without adjusting for any covariates, proportionally more caregivers in the PDD group experienced stress, followed in descending order by the AD+, PD, and ND groups. This is in line with previous findings (Lee et al., 2013; Roland & Chappell, 2017; Shin et al., 2012; Svendsboe et al., 2016). However, when adjusting for caregiver and client risk factors, it became apparent that caregivers in the AD+ group were at higher risk of experiencing stress, which is in line with findings by Mitchell et al. (2015). Of note is however, that Mitchell et al.'s study did not distinguish between PD and PDD, and in our study we expected that caregivers in the PDD group would be at higher risk of carer stress than caregiver in the AD+ group. This result was unexpected and suggests that having a diagnosis of Alzheimer's disease and related dementias, predicts caregiver stress above and beyond known correlates of caregiver stress. It may be possible, that the uneven distribution of sample sizes across groups explains this unexpected result, such that the almost three times larger sample size in the AD+ group compared to the PDD group asserted more influence when the combined sample was analysed.

Across groups, 15-36% of carers were rated as experiencing stress, which was very similar to Mitchell et al.'s findings, but which was substantially lower compared to another study, which found that 65% of carers had depressive symptoms (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). This discrepancy may be explained by the measure of caregiver stress in this study. The presence or absence of carer stress was assessor-rated, which may not be

as sensitive as a self-report measure and likely underestimated subtle signs of carer stress. Additionally, there may have already been support services in place to assist caregivers before the assessment, which has been found to have a protective effect on carer stress in a similar sample (Mitchell et al., 2015).

### **Client characteristics**

Client characteristics also varied significantly across groups in this sample. There was a higher prevalence of female clients in the AD+ and control groups, whereas both Parkinson's disease groups had a higher prevalence of male clients. As alluded to above, the highest proportion of married clients was in the PDD group, followed in descending order by clients in PD, AD+ and ND groups. Being married, looking after a male client, and presence of financial hardship increased the risk of caregiver stress. When the groups were analysed separately, only caregivers in the control group experienced increased risk of carer stress when being married and experiencing financial burden.

In terms of cognitive status, cognitive impairment was more prevalent in both dementia groups compared to the non-dementia groups, however memory problems were frequent across all groups, highlighting the presence of complex health needs that are characteristic of this sample. There were no differences between proportions of clients in the PDD and AD+ groups in terms of cognitive function variables. The prevalence of cognitive fluctuation was equal in the PDD and AD+ groups. Problems with short-term memory were more common in clients with AD+, which is in line with a previous finding (Aarsland et al., 2003), however there was only a three percentage point difference compared to the PDD group, which was not deemed to represent a meaningful difference, and therefore short-term memory problems were highly prevalent in both dementia groups.

Of the cognitive function predictors, problems with decision making and short-term memory were related to caregiver stress. When the diagnostic groups were analysed separately, problems with short-term memory were only predictive of carer stress in the PDD group, which was surprising, because it was expected to be related to AD+ as well. The ratings for cognitive status variables were determined by trained assessors; a refined neuropsychiatric assessment may deliver different results. Standardised neuropsychological memory tests are likely to deliver more fine grained and reliable results than the clinically used screening tools of the InterRAI-HC (Lockie, 2018). Alternatively, it is possible that problems with short-term memory in a client with Parkinson's disease can lead to forgetting caregiver requests regarding ambulation safety, which likely necessitates repeated reminders that caregivers may experience as frustrating and stressful (Roland et al., 2010).

In this sample, the proportion of clients with Parkinson's disease who experienced falls was substantially higher compared to a study by Schrag et al. (2006), and was highest in those with PDD (61%). This result may reflect the nature of this sample containing clients with significant health needs. Falls were more prevalent in clients with PDD compared to AD+, which is in line with previous findings (Evatt et al., 2008). There was no significant difference in the proportion of individuals experiencing falls in the past 90 days between the two Parkinson's disease groups, so proportionally more clients in these groups experienced falls than clients in the non-Parkinson's disease groups. Risk of carer stress was found to increase with the presence of falls. Thus, the results suggest that experiencing falls is related to carer stress and that caregivers of clients with Parkinson's disease may be particularly vulnerable due to the proportionally higher rate of falls in this client group. When analysed by group, the odds ratios for the Parkinson's

groups were sizeable, albeit not statistically significant, thereby possibly presenting a potential power problem.

The prevalence of hallucinations, delusions and abnormal thought was highest in the PDD group compared to all other groups. This is in line with previous results (Aarsland, Larsen, Karlsen, Lim, & Tandberg, 1999; Carod-Artal, Mesquita, Ziomkowski, & Martinez-Martin, 2013; Lee, McKeith, Mosimann, Ghosh-Nodyal, & Thomas, 2013; Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006). Only delusions increased the risk of carer stress when the combined sample was analysed. When the sample was analysed by groups however, the results were mixed. For example, delusions only related to carer stress in the AD+ and ND groups, which may reflect the presence of psychiatric disorders rather than dementia related psychiatric symptoms in the control group, or a power problem in the PDD group. It was surprising that psychotic symptoms were not related to carer stress in the PDD group, and this may be due to larger sample sizes in other groups increasing the likelihood of meeting the threshold for statistical significance.

Sleep disturbance occurred in roughly one third of clients and was more common in both Parkinson's disease groups than non-Parkinson's disease groups. Rongve, Boeve, and Aarsland (2010) report that people with Parkinson's disease experience more sleep-related problems (vivid dreams) compared to patients with Alzheimer's disease, which is in line with our findings. Client sleep disturbance was related to carer stress, however when analysed by group, there was no relation to carer stress in the PDD group, which was surprising. The variable sleep disturbance included endorsements of too little sleep as well as too much sleep, whereby the latter may not be as strongly related to caregiver stress as the former, possibly resulting in the need for more

power to detect a relationship with caregiver stress. Although, one study has found a relationship specifically between day-time sleepiness and caregiver stress (Lee et al., 2013).

Depression ratings were related to caregiver stress, which is consistent with past literature that established it as a key risk factor for caregiver stress (Chiu et al., 2016; Lee et al., 2013; Mosley et al., 2017; Santos-García & de la Fuente-Fernández, 2015; Schrag et al., 2006; Shin et al., 2012; Viwattanakulvanid et al., 2014; Zhong et al., 2016).

Problem behaviours were common in both dementia groups and there was no difference between the PDD and AD+ groups, which is contrary to past findings (Feast et al., 2016; Thommessen et al., 2002). Risk of carer stress increased in the presence of all problem behaviours (wandering, verbal abuse and resistance of care), with verbal abuse standing out as especially stressful. When the sample was analysed by groups, wandering appeared to be especially stressful for caregivers of PDD clients. Dementia related wandering behaviour increases the risk of falls especially within the context of Parkinson's disease related motor problems, which may relate to caregiver stress in a variety of ways. For example, the imposed need for constant vigilance may be mentally straining and failure to prevent injury may lead to feelings of guilt; increased reprimands in an attempt to prevent falls, may lead to family conflict and tension (Roland et al., 2010).

Summarising client characteristics, it could be said that cognitive impairment and problem behaviours were more prevalent in the dementia groups; both Parkinson's disease groups had higher proportions of clients experiencing falls and sleep disturbance; and clients in the PDD group, had the highest prevalence of psychotic symptoms but this did not always relate to caregiver stress.

Findings of the separate group analyses were explorative. Total hours of care, co-habitation, client decision making problems, disturbed sleep and decrease in client social activities emerged as predictors of caregiver stress for all groups, except the PDD group, which is possibly due to a power problem. Therefore, it could be said that these predictors may be generally related to caregiver stress, independent of the underlying neurodegenerative disease or presence of dementia. In addition to these predictors, hallucinations in the PD group also emerged within the three strongest predictors of carer stress. Presence of short-term memory problems, wandering behaviour and presence of a second carer emerged as the three strongest predictors of caregiver stress in the PDD group. In the AD+ and ND groups, co-habitation, presence of client decision making problems and verbal abuse were among the top three risk factors for caregiver stress. It is important to recognise that the control group contained clients with other neurological diseases such as Huntington's disease and potentially the presence of undiagnosed dementia, which may explain the similar predictors of caregiver stress compared to the AD+ group.

### **Client social integration**

Very few studies have examined client social integration and its effects on caregivers within a Parkinson's disease context; this study extends the literature in this regard. The client psychosocial characteristics we examined included presence of a second caregiver, frequency of social contact, loneliness and decline in social activities. It was found that over 65% had a second caregiver and less than one quarter of clients across groups felt lonely. In terms of participation in social activities and frequency of social contact, clients in the PDD group were worse off compared to clients in other groups. The inclusion of psychosocial predictors in the logistic model explained a small but significant amount of variance in caregiver stress. Presence of a second carer and greater social contact frequency were small but significant protective

factors; loneliness and a decrease in social activities were risk factors for caregiver stress. It is important to highlight that these effects emerged after controlling for all other predictors in the models and the large sample size made it possible to find such effects, albeit small.

Previous longitudinal studies have found that a socially integrated lifestyle may be protective of dementia (Fratiglioni, Paillard-Borg, & Winblad, 2004; Wang, 2002). We did not examine interactions among predictors, and it may be the case that healthier clients were still able to participate in social activities, which may explain the relationship to caregiver stress. However, psychosocial predictors were added as a last step in logistic regressions, so the model did control for demographic, disease and client predictors of caregiver stress. An alternative explanation for these results is that the quality of the relationships and social interactions had an impact on client as well as caregiver wellbeing, such that harmonious families may have more frequent contact and are perceived as supportive, which in turn has positive effects on caregivers (Amieva et al., 2010).

### **Strengths and Limitations**

There are several limitations that are important to be aware of when interpreting the findings. The way the sample was subdivided into the four diagnostic groups may be worth considering with regards to the AD+ group, which included clients with vascular, frontotemporal and Lewy Body dementias. Lewy body dementia is clinically very similar to Parkinson's disease related dementia and because the nature of the dataset did not allow examination of the AD+ group, it was impossible to determine the distribution of dementia types within the AD+ group. The presence of a large proportion of clients with Lewy Body Dementia in this group, may have had a diluting effect when compared to clients with Parkinson's disease related dementia. With regards to the PD group, it was evident that there was some cognitive impairment and past

research indicates that around 25% of clients with Parkinson's disease meet the criteria of mild cognitive decline (Aarsland et al., 2010). If this was the case in the current study, comparison effects between PD and PDD groups may have been diluted, because the potential effects of even mild cognitive impairment on caregiver stress (Jones et al., 2017).

The sample size in each of the four groups had large differences ranging between 534 – 50379 participants, which was reflected in the separate logistic regression analyses by diagnostic group, whereby the total number of odds ratios that met the statistical significance threshold was higher in the groups with a larger sample size, i.e. AD+ and ND. Therefore, the size of odds ratios should take precedence when interpreting results especially from these groups. Particularly in the PDD group, some odds ratios did not meet statistical significance and contradicted findings from previous literature. It is possible that measurement errors were offset by groups with a substantial sample size and thus had a less pronounced impact on the results but a more significant impact on groups with a smaller sample size, such as the PDD group. This is important to consider when drawing conclusions about the PDD group, which on several predictor variables came out as most vulnerable in univariate analyses, however did not meet statistical significance on several key predictors of caregiver stress.

Sources of measurement error in this sample also warrant mentioning. The national implementation InterRAI-HC was recent and it is normal for there to be inconsistencies in measuring a large number of variables by different assessors. While assessor training aims for the most reliable assessment, measurement discrepancies may stem from the differences in training background for assessors. As such it is possible, that a nurse assessor may emphasise slightly different areas in the assessment compared to a social worker assessor (physical versus psychosocial areas of functioning), and as mentioned above, the smaller the sample size, the

more such inconsistencies affect the results. The study's purpose was to examine this New Zealand sample, therefore generalisability is limited by the nature of this sample and distribution of demographic variables across the groups.

The study focused on risk factors that were strongly related to stress in carers of clients with Parkinson's disease. Other related factors such as caregiver gender, age, duration of caring, coping strategies and availability of formal supports were not available from the dataset. The same applies for key client psychiatric predictors such as apathy and anxiety. Due to the unavailability of caregiver gender data, it was difficult to determine whether female carers or presence of male clients were responsible for the increased odds of carer stress. As Parkinson's disease and dementia progress, it seems logical for caregiver burden to increase due to increased functional and cognitive impairment (Zhong et al., 2016). However, two large reviews have found that disease duration and stage are less predictive of caregiver burden than cognitive impairment (Greenwell et al., 2015; Leiknes et al., 2015). Additionally, Schrag et al. (2006) found these variables depended on the carer stress outcome variable (i.e. significant for burden and quality of life but not depression).

The outcome variable was a dichotomous measure, only indicating the presence or absence of caregiver stress as rated by a clinical assessor in relation to the primary caregiver, and which did not provide levels of carer stress. Future research could address potential sensitivity issues with this measure by comparing it to a validated self-rating measure or the Zarit Caregiver Burden Interview (Zarit, Reever & Bach-Peterson, 1980). The study used cross-sectional data, which limits any causal explanations, but future studies can easily address this by utilising the now available long-term data on these clients. The study also did not examine interactions between risk factors.

The study provided a large amount of data on community based caregivers with complex health needs. The large sample presented a number of benefits. It enabled the subgroup analysis of caregiver type, which adds to the current literature; it made it possible to subdivide the sample to investigate similarities and differences across different neurodegenerative diseases; it identified small but intriguing findings with regard to client psychosocial predictors for caregiver stress. Another strength is that this sample consisted of older adults with complex health needs, which would make it more difficult to find differences between groups, thereby providing robust findings as to differences between groups.

### **Implications of findings**

Despite some mixed findings in this study, there was a trend to suggest that clients and caregivers in the PDD group are worse off than other groups on a number of risk factors. With regards to the Parkinson's disease groups, it is noteworthy that the presence of a second caregiver was a protective factor. These results may be useful for assessors to take into consideration when organizing and implementing support services for families who want to keep clients in their preferred living arrangements and who aspire to limit the adverse health impacts on caregivers. This could entail the provision of more services, paying special attention to the caregiver network and finding ways to support the caregiver by integrating another caregiver to help out. Client social integration appeared to be related to caregiver stress, which supports community organisations that work toward maintaining patient social ties.

### **Future directions**

Future studies could contribute to the literature by drawing a random sample from the InterRAI-HC dataset and even out proportions across diagnostic groups in order to minimise

effects of geographical sampling bias and uneven distribution of group sample size.

Alternatively, studies could examine whether results are upheld after using resampling methods such as bootstrapping to even out sample sizes across groups. Additionally, results may be easier to interpret if future researchers can exclude clients with Lewy body dementia, which are thought to possibly have diluted results in this study. In terms of caregiver data, additional information could be collected in order to control for caregiver demographic characteristics and stage of disease. The outcome variable could be enhanced and validated using a validated measure such as the Zarit caregiver burden interview. Controlling for formal support services would further improve future studies. The InterRAI-HC measures appear to perform satisfactorily when the sample is large enough, but may be less accurate to detect impairments within cognitive domains (e.g. short term memory or cognitive fluctuations). Future studies should therefore use neuropsychiatric testing or use samples that are large enough for fine grained analyses of individual cognitive and neuropsychiatric predictors.

## **Conclusions**

In conclusion, caregiver and client characteristics varied significantly across diagnostic groups. Across groups, a mixed pattern of risk factors emerged. Compared to clients in other diagnostic groups, clients with Parkinson's disease related dementia (PDD) were worse off on a number of risk factors including hours of care, support with activities of daily living, hallucinations, delusions, and abnormal thought, with wandering appearing to be especially stressful. Being classified in this group however, did not appear to be a risk factor for caregiver stress; instead being classified into the Alzheimer's and related dementias group emerged as a risk factor for caregiver stress, even after accounting for client and carer characteristics.

However, the caregiver and client characteristics had a stronger impact on caregiver stress than

the simple categorisation into diagnostic groups. The social integration of clients made a small but significant contribution to caregiver stress, which is a valuable contribution to a sparse literature. It is crucial to examine these findings in the context of the study's limitations, most notably the large differences in sample size across groups, which future studies should address. These findings may be useful for InterRAI-HC assessors when taking into account caregiver stress during service need assessments of clients with different dementia types.

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<b>2. ETHNICITY</b> [check at least one but no more than three options]	
10 European not further defined	41 Southeast Asian
11 New Zealand European	42 Chinese
12 Other European	43 Indian
21 Māori	44 Other Asian
30 Pacific peoples not further defined	51 Middle Eastern
31 Samoan	52 Latin American / Hispanic
32 Cook Island Māori	53 African (or any group of African origin)
33 Tongan	61 Other ethnicity
34 Niuean	94 Don't know
35 Tokelauan	95 Refused to answer
36 Fijian	97 Response unidentifiable
37 Other Pacific peoples	99 Not stated
40 Asian not further defined	

**3. PRIMARY LANGUAGE** [see manual for codes]

<b>4. RESIDENTIAL HISTORY OVER LAST 5 YEARS</b> Code for all settings person lived in during 5 YEARS prior to date stay began (Item B1) 0. No 1. Yes	
a. Long-term care facility—e.g., nursing home	<input type="checkbox"/>
b. Board and care home or assisted living	<input type="checkbox"/>
c. Mental health residence—e.g., psychiatric group home	<input type="checkbox"/>
d. Psychiatric hospital or unit	<input type="checkbox"/>
e. Setting for persons with intellectual disability	<input type="checkbox"/>

### SECTION C: COGNITION

<b>1. COGNITIVE SKILLS FOR DAILY DECISION MAKING</b> Making decisions regarding tasks of daily life—(e.g., when to get up or have meals, which clothes to wear, or activities to do.)	
0. INDEPENDENT—decisions consistent/reasonable/safe	<input type="checkbox"/>
1. MODIFIED INDEPENDENCE—some difficulty in new situations only	
2. MINIMALLY IMPAIRED—in specific situations, decisions become poor or unsafe and cues/supervision necessary at those times	
3. MODERATELY IMPAIRED—decisions consistently poor or unsafe, cues/supervision required at all times	
4. SEVERELY IMPAIRED—Never/rarely made decisions	
5. NO DISCERNIBLE CONSCIOUSNESS, COMA (skip to Section G)	

<b>2. MEMORY RECALL ABILITY</b> Code for recall of what was learned or known 0. Yes, memory OK 1. Memory problem	
a. Short-term memory OK - seems/appears to recall after five minutes	<input type="checkbox"/>
b. Procedural memory OK - can perform all or almost all steps in a multitask sequence without cues	<input type="checkbox"/>
c. Situational memory OK - Both; recognizes caregiver's name/faces frequently encountered AND knows location of places regularly visited (bedroom, dining room, activity room, therapy room)	<input type="checkbox"/>

<b>3. PERIODIC DISORDERED THINKING OR AWARENESS</b> Note: Accurate assessment requires conversations with staff, family, or others who have direct knowledge of the person's behaviour over time.	
0. Behaviour not present	
1. Behaviour present, consistent with usual functioning	
2. Behaviour present, appears different from usual functioning (e.g. new onset or worsening; different from a few weeks ago)	

a. Easily distracted e.g. episodes of difficulty paying attention, gets side-tracked	<input type="checkbox"/>
b. Episodes of disorganised speech e.g. speech is nonsensical, irrelevant, or rambling from subject to subject; loses train of thought	<input type="checkbox"/>
c. Mental function varies over the course of the day e.g. sometimes better, sometimes worse	<input type="checkbox"/>

<b>4. ACUTE CHANGE IN MENTAL STATUS FROM PERSON'S USUAL FUNCTIONING</b> E.g. restlessness, lethargy, difficulty to arouse, altered environmental perception 0. No 1. Yes	
	<input type="checkbox"/>

<b>5. CHANGE IN DECISION MAKING</b> As compared to 90 days ago (or since last assessment)	
0. Improved	2. Declined
1. No change	8. Uncertain
	<input type="checkbox"/>

### SECTION D: COMMUNICATION AND VISION

<b>1. MAKING SELF UNDERSTOOD (EXPRESSION)</b> Expressing information content—both verbal and non-verbal	
0. UNDERSTOOD—Expresses ideas without difficulty	<input type="checkbox"/>
1. USUALLY UNDERSTOOD—Difficulty finding words or finishing thoughts BUT if given time, little or no prompting usually required	
2. OFTEN UNDERSTOOD—Difficulty finding words or finishing thoughts AND prompting usually required	
3. SOMETIMES UNDERSTOOD—Ability is limited to making concrete requests	
4. RARELY/NEVER UNDERSTOOD	

<b>2. ABILITY TO UNDERSTAND OTHERS (COMPREHENSION)</b> Understanding verbal information content (however able); with hearing aid normally used	
0. UNDERSTANDS—clear comprehension	<input type="checkbox"/>
1. USUALLY UNDERSTANDS—misses some part/intent of message, BUT comprehends most conversation	
2. OFTEN UNDERSTANDS—misses some part/intent of message BUT with repetition or explanation can often comprehend conversation	
3. SOMETIMES UNDERSTANDS—responds adequately to simple, direct communication	
4. RARELY/NEVER UNDERSTANDS	

<b>3. HEARING</b> Ability to hear (With hearing aid normally used)	
0. ADEQUATE—No difficulty in normal conversation, social interaction, listening to TV	<input type="checkbox"/>
1. MINIMAL DIFFICULTY—Difficulty in some environments (e.g., when person speaks softly or is more than 2 metres away)	
2. MODERATE DIFFICULTY—Problem hearing normal conversation, requires quiet setting to hear well	
3. SEVERE DIFFICULTY—Difficulty in all situations (e.g., speaker has to talk loudly or speak very slowly; or person reports that all speech is mumbled)	
4. NO HEARING	

<b>4. VISION</b> Ability to see in adequate light (with glasses or with other visual aid normally used)	
0. ADEQUATE—Sees fine detail, including regular print in newspapers/books	<input type="checkbox"/>
1. MINIMAL DIFFICULTY—Sees large print, but not regular print in newspapers/books	
2. MODERATE DIFFICULTY—Limited vision; not able to see newspaper headlines, but can identify objects	
3. SEVERE DIFFICULTY—Object identification in question, but eyes appear to follow objects; sees only light, colours, shapes	
4. NO VISION	

SECTION E: MOOD AND BEHAVIOUR	
<p><b>1. INDICATORS OF POSSIBLE DEPRESSED, ANXIOUS, SAD MOOD</b></p> <p>Code for indicators observed in last 3 days, irrespective of the assumed cause [Note: whenever possible, ask person.]</p> <p>0. Not present            1. Present but not exhibited in last 3 days            2. Exhibited on 1-2 of last 3 days            3. Exhibited daily in last 3 days</p> <p><b>a. MADE NEGATIVE STATEMENTS</b>            e.g. "Nothing matters." "Would rather be dead.", "What's the use.", "Let me die." <input type="checkbox"/></p> <p><b>b. PERSISTENT ANGER WITH SELF OR OTHERS</b>            e.g. easily annoyed, anger at care received <input type="checkbox"/></p> <p><b>c. EXPRESSIONS, INCLUDING NONVERBAL, OF WHAT APPEAR TO BE UNREALISTIC FEARS</b>            e.g., fear of being abandoned, left alone, or being with others; intense fear of specific objects or situations <input type="checkbox"/></p> <p><b>d. REPETITIVE HEALTH COMPLAINTS</b>            e.g., persistently seeks medical attention, incessant concern with body functions <input type="checkbox"/></p> <p><b>e. REPETITIVE ANXIOUS COMPLAINTS/CONCERNS</b>            non health-related e.g., persistently seeks attention/reassurance regarding schedules, meals, laundry, clothing, relationships <input type="checkbox"/></p> <p><b>f. SAD, PAINED, WORRIED FACIAL EXPRESSIONS</b>            e.g., furrowed brow, constant frowning <input type="checkbox"/></p> <p><b>g. CRYING, TEARFULNESS</b> <input type="checkbox"/></p> <p><b>h. RECURRENT STATEMENTS THAT SOMETHING TERRIBLE IS ABOUT TO HAPPEN</b>            e.g., believes he or she is about to die, have a heart attack <input type="checkbox"/></p> <p><b>i. WITHDRAWAL FROM ACTIVITIES OF INTEREST</b>            e.g., no interest in long standing activities or being with family or friends <input type="checkbox"/></p> <p><b>j. REDUCED SOCIAL INTERACTION</b> <input type="checkbox"/></p> <p><b>k. EXPRESSIONS, INCLUDING NONVERBAL, OF A LACK OF PLEASURE IN LIFE (ANHEDONIA)</b>            e.g., "I don't enjoy anything anymore." <input type="checkbox"/></p>	
<p><b>2. SELF-REPORTED MOOD</b></p> <p>0. Not in the last 3 days            1. Not in the last 3 days, but often feels that way            2. In 1-2 of the last 3 days            3. Daily in the last 3 days            8. Person could not (would not) respond</p> <p>Ask: "In the last 3 days, how often have you felt..."</p> <p>a. Little interest or pleasure in things you normally enjoy? <input type="checkbox"/></p> <p>b. Anxious, restless, or uneasy? <input type="checkbox"/></p> <p>c. Sad, depressed, or hopeless? <input type="checkbox"/></p>	
<p><b>3. BEHAVIOURAL SYMPTOMS</b></p> <p>Code for indicators observed, irrespective of the assumed cause</p> <p>0. Not present            1. Present but not exhibited in last 3 days            2. Exhibited on 1-2 of last 3 days            3. Exhibited daily in last 3 days</p> <p><b>a. WANDERING</b> moving with no rational purpose, seemingly oblivious to needs or safety <input type="checkbox"/></p> <p><b>b. VERBAL ABUSE</b> others were threatened, screamed at cursed at <input type="checkbox"/></p> <p><b>c. PHYSICAL ABUSE</b> Others were hit, shoved, scratched sexually abused <input type="checkbox"/></p> <p><b>d. SOCIALLY INAPPROPRIATE/DISRUPTIVE BEHAVIOUR</b> made disruptive sounds or noises, screamed out, smeared or threw food or faeces, hoarded, rummaged through other's belongings <input type="checkbox"/></p>	

<p>e. INAPPROPRIATE PUBLIC SEXUAL BEHAVIOUR OR PUBLIC DISROBING <input type="checkbox"/></p> <p>f. RESISTS CARE taking medications/injections, ADL assistance, eating <input type="checkbox"/></p>					
SECTION F: PSYCHOSOCIAL WELL-BEING					
<p><b>1. SOCIAL RELATIONSHIPS</b> [Note: Whenever possible, ask person]</p> <p>0. Never            1. More than 30 days ago            2. 8-30 days ago            3. 4-7days ago            4. In last 3 days            8. Unable to determine</p> <p>a. Participation in social activities of long-standing interest <input type="checkbox"/></p> <p>b. Visit with a long-standing social relation or family member <input type="checkbox"/></p> <p>c. Other interaction with long-standing social relation or family member—e.g., telephone, e-mail <input type="checkbox"/></p> <p>d. Conflict or anger with family or friends <input type="checkbox"/></p> <p>e. Fearful of a family member or close acquaintance <input type="checkbox"/></p> <p>f. Neglected, abused, or mistreated <input type="checkbox"/></p>					
<p><b>2. LONELY</b></p> <p>Says or indicates that he/she feels lonely 0. No 1. Yes <input type="checkbox"/></p>					
<p><b>3. CHANGE IN SOCIAL ACTIVITIES IN LAST 90 DAYS</b>            [or since last assessment if less than 90 days ago]</p> <p>Decline in level of participation in social, religious, occupational, or other preferred activities. IF THERE WAS A DECLINE, person distressed by this fact.</p> <p>0. No Decline            1. Decline, not distressed            2. Decline, distressed <input type="checkbox"/></p>					
<p><b>4. LENGTH OF TIME ALONE DURING THE DAY</b>            Morning and afternoon</p> <p>0. Less than 1 hour            1. 1-2 hours            2. More than 2 hours but less than 8 hours            3. 8 hours or more <input type="checkbox"/></p>					
<p><b>5. MAJOR LIFE STRESSORS IN LAST 90 DAYS</b>            e.g. episode of severe personal illness; death or severe illness of close family member/friend; loss of home; major loss of income/assets; victim of a crime such as robbery; loss of driving license/car</p> <p>0. No 1. Yes <input type="checkbox"/></p>					
SECTION G: FUNCTIONAL STATUS					
<p><b>1. IADL SELF-PERFORMANCE AND CAPACITY</b></p> <p>0. INDEPENDENT—No help, setup, or supervision            1. SETUP HELP ONLY            2. SUPERVISION—Oversight/cuing            3. LIMITED ASSISTANCE—Help on some occasions            4. EXTENSIVE ASSISTANCE—Help throughout task, but performs 50% or more of task on own            5. MAXIMAL ASSISTANCE—Help throughout task, but performs less than 50% of task on own            6. TOTAL DEPENDENCE—Full performance by others during entire period            8. ACTIVITY DID NOT OCCUR DURING ENTIRE PERIOD * do not use this for coding (B) CAPACITY</p>					
<p>(A) Code for PERFORMANCE in routine activities around the home or in the community during the LAST 3 DAYS.</p> <p>(B) Code for CAPACITY based on presumed ability to carry out activity as independently as possible. This will require "speculation" by the assessor.</p>	<table border="1"> <thead> <tr> <th>PERFORMANCE</th> <th>CAPACITY</th> </tr> </thead> <tbody> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </tbody> </table>	PERFORMANCE	CAPACITY	<input type="checkbox"/>	<input type="checkbox"/>
PERFORMANCE	CAPACITY				
<input type="checkbox"/>	<input type="checkbox"/>				

<b>a. MEAL PREPARATION</b>	How meals are prepared (e.g., planning meals, cooking, assembling ingredients, setting out food and utensils)	<input type="checkbox"/>	<input type="checkbox"/>
<b>b. ORDINARY HOUSEWORK</b>	How ordinary work around the house is performed (e.g., doing dishes, dusting, making bed, tidying up, laundry)	<input type="checkbox"/>	<input type="checkbox"/>
<b>c. MANAGING FINANCES</b>	How bills are paid, cheque book is balanced, household expenses are budgeted, credit card account is monitored	<input type="checkbox"/>	<input type="checkbox"/>
<b>d. MANAGING MEDICATIONS</b>	How medications are managed (e.g., remembering to take medicines, opening bottles, taking correct drug dosages, giving injections, applying ointments)	<input type="checkbox"/>	<input type="checkbox"/>
<b>e. PHONE USE</b>	How telephone calls are made or received (with assistive devices such as large numbers on telephone, amplification as needed)	<input type="checkbox"/>	<input type="checkbox"/>
<b>f. STAIRS</b>	How full flight of stairs is managed (12–14 stairs)	<input type="checkbox"/>	<input type="checkbox"/>
<b>g. SHOPPING</b>	How shopping is performed for food and household items (e.g., selecting items, paying money) EXCLUDE TRANSPORTATION	<input type="checkbox"/>	<input type="checkbox"/>
<b>h. TRANSPORTATION</b>	How travels by public transportation (navigating system, paying fare) or driving self (including getting out of house, into and out of vehicles)	<input type="checkbox"/>	<input type="checkbox"/>
<b>2. ADL SELF-PERFORMANCE</b>	Consider all episodes over 3-day period		
	<p>0. <b>INDEPENDENT</b>—No physical assistance, setup, or supervision in any episode</p> <p>1. <b>INDEPENDENT, SETUP HELP ONLY</b>—Article or device provided or placed within reach, no physical assistance or supervision in any episode</p> <p>2. <b>SUPERVISION</b>—Oversight/cuing</p> <p>3. <b>LIMITED ASSISTANCE</b>—Guided manoeuvring of limbs, physical guidance without taking weight</p> <p>4. <b>EXTENSIVE ASSISTANCE</b>—Weight-bearing support (including lifting limbs) by 1 helper where person still performs 50% or more of subtasks</p> <p>5. <b>MAXIMAL ASSISTANCE</b>—Weight-bearing support (including lifting limbs) by 2+ helpers—OR—Weight-bearing support for more than 50% of subtasks</p> <p>6. <b>TOTAL DEPENDENCE</b>—Full performance by others during all episodes</p> <p>8. <b>ACTIVITY DID NOT OCCUR DURING ENTIRE PERIOD</b></p> <p>If all episodes are performed at the same level, score ADL at that level.</p> <p>If any episodes at level 6, and others less dependent, score ADL as a 5.</p> <p>Otherwise, focus on the three most dependent episodes [or all episodes if performed fewer than 3 times] If most dependent episode is 1, score ADL as 1. If not, score ADL as least dependent of those episodes in range 2–5.</p>		
<b>a. BATHING</b>	How takes full-body bath/shower. Includes how transfers in and out of bath or shower AND how each part of body is bathed: arms, upper and lower legs, chest, abdomen, perineal area - EXCLUDE WASHING OF BACK AND HAIR	<input type="checkbox"/>	<input type="checkbox"/>
<b>b. PERSONAL HYGIENE</b>	How manages personal hygiene, including combing hair, brushing teeth, shaving, applying makeup, washing/drying face and hands EXCLUDE BATHS AND SHOWERS	<input type="checkbox"/>	<input type="checkbox"/>

<b>c. DRESSING UPPER BODY</b>	How client dresses and undresses (street clothes, underwear) above the waist, included prostheses, orthotics, fasteners, pullovers, etc.	<input type="checkbox"/>	<input type="checkbox"/>
<b>d. DRESSING LOWER BODY</b>	How client dresses and undresses (street clothes, underwear) from the waist down, includes prostheses, orthotics, belts, pants, skirts, shoes, and fasteners	<input type="checkbox"/>	<input type="checkbox"/>
<b>e. WALKING</b>	How walks between locations on same floor indoors	<input type="checkbox"/>	<input type="checkbox"/>
<b>f. LOCOMOTION</b>	How moves between locations on same floor (walking or wheeling). If in wheelchair, self-sufficiency once in chair	<input type="checkbox"/>	<input type="checkbox"/>
<b>g. TRANSFER TOILET</b>	How moves on and off toilet or commode	<input type="checkbox"/>	<input type="checkbox"/>
<b>h. TOILET USE</b>	How uses the toilet room (or commode, bedpan, urinal), cleans self after toilet use or incontinent episode(s), changes pad, manages ostomy or catheter, adjusts clothes EXCLUDES TRANSFER ON AND OFF TOILET	<input type="checkbox"/>	<input type="checkbox"/>
<b>i. BED MOBILITY</b>	How moves to and from lying position, turns from side to side, and positions body while in bed	<input type="checkbox"/>	<input type="checkbox"/>
<b>j. EATING</b>	How eats and drinks (regardless of skill). Includes intake of nourishment by other means (e.g., tube feeding, total parenteral nutrition)	<input type="checkbox"/>	<input type="checkbox"/>
<b>3. LOCOMOTION/WALKING</b>	<input type="checkbox"/>		
<b>a. PRIMARY MODE OF LOCOMOTION</b>	<p>0. Walking, no assistive device</p> <p>1. Walking, uses assistive device—walking stick, walker, crutch, pushing wheelchair</p> <p>2. Wheelchair, scooter</p> <p>3. Bed-bound</p>		
<b>b. TIMED 4 METRE WALK</b>	<p>Lay out a straight, unobstructed course. Have person stand in still position, feet just touching start line.</p> <p>Then say: "When I tell you, begin to walk at a normal pace (with walking stick / walker if used). This is not a test of how fast you can walk. Stop when I tell you to stop. Is this clear?" Assessor may demonstrate test.</p> <p>Then say: "Begin to walk now." Start stopwatch (or can count seconds) when first foot falls. End count when foot falls beyond 4-metre mark.</p> <p>Then say: "You may stop now."</p> <p>Enter time in seconds, up to 30 seconds</p> <p>30. 30 or more seconds to walk 4 metres <input type="checkbox"/></p> <p>77. Stopped before test complete <input type="checkbox"/></p> <p>88. Refused to do the test</p> <p>99. Not tested—e.g., does not walk on own</p>		
<b>c. DISTANCE WALKED</b>	<p>Farthest distance walked at one time without sitting down in the LAST 3 DAYS (with support as needed)</p> <p>0. Did not walk</p> <p>1. Less than 5 metres</p> <p>2. 5–49 metres</p> <p>3. 50–99 metres</p> <p>4. 100+ metres</p> <p>5. 1+ kilometres <input type="checkbox"/></p>		



<b>OTHER</b>		
t. Cancer		<input type="checkbox"/>
u. Diabetes mellitus		<input type="checkbox"/>
<b>2. OTHER DISEASE</b>		
0. Not present		
1. Primary diagnosis/diagnoses for current stay		
2. Diagnosis present, receiving active treatment		
3. Diagnosis present, monitored but no active treatment		
<b>DIAGNOSIS</b>	<b>DISEASE CODE</b>	<b>ICD CODE</b>
a.		
b.		
c.		
d.		
<b>SECTION J: HEALTH CONDITIONS</b>		
<b>1. FALLS</b>		
0. No fall in last 90 days <input type="checkbox"/>		
1. No fall in last 30 days, but fell 31–90 days ago		
2. One fall in last 30 days		
3. Two or more falls in last 30 days		
<b>2. RECENT FALLS</b>		
<i>(Skip / not applicable if last assessed more than 30 days ago or if this is first assessment)</i>		
0. No 1. Yes <input type="checkbox"/>		
<b>3. PROBLEM FREQUENCY</b>		
Code for presence in last 3 days		
0. Not present		
1. Present but no exhibited in last 3 days		
2. Exhibited on 1 of last 3 days		
3. Exhibited on 2 of last 3 days		
4. Exhibited daily in last 3 days		
<b>BALANCE</b>		
a. Difficult or unable to move self to standing position unassisted		<input type="checkbox"/>
b. Difficult or unable to turn self around and face the opposite direction when standing		<input type="checkbox"/>
c. Dizziness		<input type="checkbox"/>
d. Unsteady gait		<input type="checkbox"/>
<b>CARDIAC OR PULMONARY</b>		
e. Chest pain		<input type="checkbox"/>
f. Difficulty clearing airway secretions		<input type="checkbox"/>
<b>PSYCHIATRIC</b>		
g. Abnormal thought process—e.g., loosening of associations, blocking, flight of ideas, tangentiality, circumstantiality		<input type="checkbox"/>
h. Delusions—Fixed, false beliefs		<input type="checkbox"/>
i. Hallucinations—False sensory perceptions		<input type="checkbox"/>
<b>NEUROLOGICAL</b>		
j. Aphasia		<input type="checkbox"/>
<b>GI STATUS</b>		
k. Acid reflux—Regurgitation of acid from stomach to throat		<input type="checkbox"/>
l. Constipation—No bowel movement in 3 days or difficult passage of hard stool		<input type="checkbox"/>
m. Diarrhoea		<input type="checkbox"/>

n. Vomiting		<input type="checkbox"/>
<b>SLEEP PROBLEMS</b>		
o. Difficulty falling asleep or staying asleep; waking up too early; restlessness; non-restful sleep <input type="checkbox"/>		
p. Too much sleep—Excessive amount of sleep that interferes with person's normal functioning <input type="checkbox"/>		
<b>OTHER</b>		
q. Aspiration		<input type="checkbox"/>
r. Fever		<input type="checkbox"/>
s. GI or GU bleeding		<input type="checkbox"/>
t. Hygiene - unusually poor hygiene, unkempt, dishevelled		<input type="checkbox"/>
u. Peripheral oedema		<input type="checkbox"/>
<b>4. DYSPNOEA (SHORTNESS OF BREATH)</b>		
0. Absence of symptom <input type="checkbox"/>		
1. Absent at rest, but present when performed moderate activities		
2. Absent at rest, but present when performed normal day-to-day activities		
3. Present at rest		
<b>5. FATIGUE</b>		
Inability to complete normal daily activities—e.g., ADLs, IADLs		
0. None <input type="checkbox"/>		
1. Minimal—Diminished energy but completes normal day-to-day activities		
2. Moderate—Due to diminished energy, UNABLE TO FINISH normal day-to-day activities		
3. Severe—Due to diminished energy, UNABLE TO START SOME normal day-to-day activities		
4. Unable to commence any normal day-to-day activities—Due to diminished energy		
<b>6. PAIN SYMPTOMS</b>		
<i>(Note: Always ask the person about pain frequency, intensity, and control. Observe person and ask others who are in contact with the person.)</i>		
<b>a. Frequency with which person complains or shows evidence of pain (including grimacing, teeth clenching, moaning, withdrawal when touched, or other nonverbal signs suggesting pain)</b>		
0. No pain <input type="checkbox"/>		
1. Present but not exhibited in last 3 days		
2. Exhibited on 1–2 of last 3 days		
3. Exhibited daily in last 3 days		
<b>b. Intensity of highest level of pain present</b>		
0. No pain		
1. Mild		
2. Moderate		
3. Severe		
4. Times when pain is horrible or excruciating <input type="checkbox"/>		
<b>c. Consistency of pain</b>		
0. No pain		
1. Single episode during last 3 days		
2. Intermittent		
3. Constant		
<b>d. Breakthrough pain</b> 0. No 1. Yes <input type="checkbox"/>		
Times in LAST 3 DAYS when person experienced sudden, acute flare-ups of pain		



SECTION M: MEDICATIONS																																																	
1.	<b>ALLERGY TO ANY DRUG</b> 0. No known drug allergies    1. Yes <input type="checkbox"/>																																																
2.	<b>ADHERENT WITH MEDICATIONS PRESCRIBED BY PHYSICIAN</b> 0. Always adherent <input type="checkbox"/> 1. Adherent 80% of time or more 2. Adherent less than 80% of time, including failure to purchase prescribed medications 3. No medications prescribed																																																
3.	<b>LIST OF ALL MEDICATIONS</b> List all active prescriptions and nonprescribed (over-the-counter) medications taken in the LAST 3 DAYS Note: Use computerised records if possible, hand enter only when absolute necessary. FOR EACH DRUG RECORD: a. NAME b. DOSE—A positive number such as 0.5, 5, 150, 300. [Note: Never write a zero by itself after a decimal point (X.0 mg)] c. UNIT—Code using the following list: gtts (drops)                      ml (millilitres) gm (grams)                        oz (ounces) L (litres)                            puffs mcg (micrograms)                % (percent) mEq (milli-equivalent)           units mg (milligrams)                    oth (other) d. ROUTE OF ADMINISTRATION—Code using the following list: PO (By mouth)                      IH (Inhalation) SL (Sub-lingual)                    ET (Enteral tube) IM (Intramuscular)                R (Rectal) IV (Intravenous)                    TD (Transdermal) SQ (Subcutaneous)                NAS (nasal) EYE (eye)                            Other TOP (Topical) e. FREQ—Code the number of times per day, week, or month the medication is administered using the following list: Q1H. Every hour                      Q3D. Every three days Q2H. Every two hours                Weekly, Once each week Q3H. Every three hours                2W. Two times weekly Q4H. Every four hours                3W. Three times weekly Q6H. Every six hours                 4W. Four times weekly Q8H. Every eight hours               5W. Five times weekly SD. Five times daily                 6W. Six times weekly BED. Bedtime                         1M. Monthly BID. Two times daily                 2M. Twice every month TID. Three times daily                OTH. Other QID. Four times daily QOD. Every other day f. PRN                                      g. COMPUTER-ENTERED DRUG CODE <table border="1" style="width:100%; border-collapse: collapse;"> <thead> <tr> <th rowspan="2">a. Medication Name</th> <th rowspan="2">b. Dose</th> <th rowspan="2">c. Unit</th> <th rowspan="2">d. Route</th> <th rowspan="2">e. Freq</th> <th rowspan="2">f. PRN</th> <th rowspan="2">g. Drug</th> </tr> <tr> <th>1</th> <th>2</th> <th>3</th> <th>4</th> <th>5</th> <th>6</th> </tr> </thead> <tbody> <tr><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td></tr> </tbody> </table>	a. Medication Name	b. Dose	c. Unit	d. Route	e. Freq	f. PRN	g. Drug	1	2	3	4	5	6																																			
a. Medication Name	b. Dose								c. Unit	d. Route	e. Freq	f. PRN	g. Drug																																				
		1	2	3	4	5	6																																										
SECTION N: TREATMENT AND PROCEDURES																																																	
1.	<b>PREVENTION</b> 0. No    1. Yes a. Blood pressure measured in LAST YEAR <input type="checkbox"/> b. Colonoscopy test in LAST 5 YEARS <input type="checkbox"/> c. Dental exam in LAST YEAR <input type="checkbox"/>																																																

d. Eye exam in LAST YEAR <input type="checkbox"/>	
e. Hearing exam in LAST 2 YEARS <input type="checkbox"/>	
f. Influenza vaccine in LAST YEAR <input type="checkbox"/>	
g. Mammogram or breast exam in LAST 2 YEARS (for women) <input type="checkbox"/>	
h. Pneumovax vaccine in LAST 5 YEARS or after age 65 <input type="checkbox"/>	
2. TREATMENTS AND PROGRAMMES RECEIVED OR SCHEDULED IN THE LAST 3 DAYS [or since last assessment if less than 3 days]	
0. Not ordered AND did not occur	
1. Ordered, not implemented	
2. 1-2 of last 3 days	
3. Daily in last 3 days	
<b>TREATMENTS</b>	
a. Chemotherapy <input type="checkbox"/>	h. Tracheostomy care <input type="checkbox"/>
b. Dialysis <input type="checkbox"/>	i. Transfusion <input type="checkbox"/>
c. Infection control e.g., isolation, quarantine <input type="checkbox"/>	j. Ventilator or respirator <input type="checkbox"/>
d. IV medication <input type="checkbox"/>	k. Wound care <input type="checkbox"/>
e. Oxygen therapy <input type="checkbox"/>	<b>PROGRAMMES</b>
f. Radiation <input type="checkbox"/>	l. Scheduled toileting programme <input type="checkbox"/>
g. Suctioning <input type="checkbox"/>	m. Palliative care programme <input type="checkbox"/>
	n. Turning/repositioning programme <input type="checkbox"/>
3. FORMAL CARE	
Days (A) and Total minutes (B) of care in last 7 days.	
Extent of care/treatment in LAST 7 DAYS [or since last assessment or admission, if less than 7 days] involving:	(A) Days
	(B) Mins
a. Personal care / support services	<input type="text"/>
b. Visiting nurses	<input type="text"/>
c. Household management services	<input type="text"/>
d. Meals	<input type="text"/>
e. Physiotherapy	<input type="text"/>
f. Occupational therapy	<input type="text"/>
g. Speech-language therapy services	<input type="text"/>
h. Psychological therapy (by any licensed mental health professional)	<input type="text"/>
4. HOSPITAL USE EMERGENCY ROOM USE PHYSICIAN VISIT	
Code for number of times in LAST 90 DAYS [or since last assessment if LESS THAN 90 DAYS]	
a. Inpatient acute care hospital with overnight stay <input type="text"/>	

	b. Emergency room visit (not counting overnight stay)	<input type="checkbox"/>	<input type="checkbox"/>
	c. Physician visit (or authorised assistant or practitioner)	<input type="checkbox"/>	<input type="checkbox"/>
5.	<b>PHYSICALLY RESTRAINED</b> Limbs restrained, used bed rails, restrained to chair when sitting	0. No	1. Yes <input type="checkbox"/>
<b>SECTION O: RESPONSIBILITY</b>			
1.	<b>RESPONSIBILITY / LEGAL GUARDIAN</b>	0. No	1. Yes
	a. EPOA for personal care and welfare	<input type="checkbox"/>	
	b. EPOA for property	<input type="checkbox"/>	
2.	<b>ADVANCE DIRECTIVES</b>	0. Not in place	1. In place
	a. Living will	<input type="checkbox"/>	
	b. Do not resuscitate	<input type="checkbox"/>	
	c. Do not hospitalise	<input type="checkbox"/>	
	d. Organ donation	<input type="checkbox"/>	
	e. Post mortem request	<input type="checkbox"/>	
	f. Feeding restrictions	<input type="checkbox"/>	
	g. Medication restrictions	<input type="checkbox"/>	
	h. Other treatment restrictions	<input type="checkbox"/>	
<b>SECTION P: SOCIAL SUPPORTS</b>			
1.	<b>TWO KEY INFORMAL HELPERS</b>		
	a. Relationship to person		Helper
	1. Child or child-in-law	1	2
	2. Spouse	<input type="checkbox"/>	<input type="checkbox"/>
	3. Partner/significant other	<input type="checkbox"/>	<input type="checkbox"/>
	4. Parent/guardian	<input type="checkbox"/>	<input type="checkbox"/>
	5. Sibling	<input type="checkbox"/>	<input type="checkbox"/>
	6. Other relative or whanau	<input type="checkbox"/>	<input type="checkbox"/>
	7. Friend	<input type="checkbox"/>	<input type="checkbox"/>
	8. Neighbour	<input type="checkbox"/>	<input type="checkbox"/>
	9. No informal helper	<input type="checkbox"/>	<input type="checkbox"/>
	b. Lives with person		Helper
	0. No	1	2
	1. Yes, 6 months or less	<input type="checkbox"/>	<input type="checkbox"/>
	2. Yes, more than 6 months	<input type="checkbox"/>	<input type="checkbox"/>
	8. No informal helper	<input type="checkbox"/>	<input type="checkbox"/>
	<b>AREAS OF INFORMAL HELP DURING LAST 3 DAYS</b>		
	0. No		
	1. Yes		
	8. No informal helper		
	c. IADL help	<input type="checkbox"/>	<input type="checkbox"/>
	d. ADL help	<input type="checkbox"/>	<input type="checkbox"/>

2.	<b>INFORMAL HELPER STATUS</b>	0. No	1. Yes
	a. Informal helper(s) is unable to continue caring activities—e.g., decline in health of helper makes it difficult to continue	<input type="checkbox"/>	
	b. Primary informal helper expresses feelings of distress, anger, or depression	<input type="checkbox"/>	
	c. Family or close friends report feeling overwhelmed by person's illness	<input type="checkbox"/>	
3.	<b>HOURS OF INFORMAL CARE AND ACTIVE MONITORING DURING LAST 3 DAYS</b>		
	For instrumental and personal activities of daily living in the LAST 3 DAYS, indicate the total number of hours of help received from all family, friends, and neighbours	<input type="checkbox"/>	<input type="checkbox"/>
4.	<b>STRONG AND SUPPORTIVE RELATIONSHIP WITH FAMILY</b>	0. No	1. Yes <input type="checkbox"/>
<b>SECTION Q: ENVIRONMENTAL ASSESSMENT</b>			
1.	<b>HOME ENVIRONMENT</b>		
	Code for any of the following that make home environment hazardous or uninhabitable (if temporarily in institution, base assessment on home visits)	0. No	1. Yes
	a. Disrepair of the home—e.g., hazardous clutter; inadequate or no lighting in living room, sleeping room, kitchen, toilet, corridors; holes in floor; leaking pipes	<input type="checkbox"/>	
	b. Squalid condition—e.g., extremely dirty, infestation by rats or bugs	<input type="checkbox"/>	
	c. Inadequate heating or cooling—e.g., too hot in summer, too cold in winter	<input type="checkbox"/>	
	d. Lack of personal safety—e.g., fear of violence, safety problem in going to mailbox or visiting neighbours, heavy traffic in street	<input type="checkbox"/>	
	e. Limited access to home or rooms in home—e.g., difficulty entering or leaving home, unable to climb stairs, difficulty manoeuvring within rooms, no railings although needed	<input type="checkbox"/>	
2.	<b>LIVES IN APARTMENT OR HOUSE RE-ENGINEERED ACCESSIBLE FOR PERSONS WITH DISABILITIES</b>	0. No	1. Yes <input type="checkbox"/>
3.	<b>OUTSIDE ENVIRONMENT</b>	0. No	1. Yes
	a. Availability of emergency assistance—e.g., telephone, alarm response system	<input type="checkbox"/>	
	b. Accessibility to grocery store without assistance	<input type="checkbox"/>	
	c. Availability of home delivery of groceries	<input type="checkbox"/>	
4.	<b>FINANCES</b>		
	Because of limited funds, during the last 30 days made trade-offs among purchasing any of the following: adequate food, shelter, clothing; prescribed medications; sufficient home heat or cooling; necessary health care	0. No	1. Yes <input type="checkbox"/>
<b>SECTION R: DISCHARGE POTENTIAL AND OVERALL STATUS</b>			
1.	<b>ONE OR MORE CARE GOALS MET IN THE LAST 90 DAYS</b> (Or since last assessment if less than 90 days)	0. No	1. Yes <input type="checkbox"/>

2.	<p><b>OVERALL SELF- SUFFICIENCY HAS CHANGED SIGNIFICANTLY AS COMPARED TO STATUS OF 90 DAYS AGO</b></p> <p>(Or since last assessment if less than 90 days) <input type="checkbox"/></p> <p>0. Improved [skip to Section 5]  1. No change [skip to section 5]  2. Deteriorated</p>				
<p><b>CODE FOLLOWING THREE ITEMS IF "DETERIORATED" IN LAST 90 DAYS— OTHERWISE SKIP TO SECTION 5</b></p>					
3.	<p><b>NUMBER OF 10 ADL AREAS IN WHICH PERSON WAS INDEPENDENT PRIOR TO DETERIORATION</b> <input type="checkbox"/></p>				
4.	<p><b>NUMBER OF 8 IADL PERFORMANCE AREAS IN WHICH PERSON WAS INDEPENDENT PRIOR TO DETERIORATION</b> <input type="checkbox"/></p>				
5.	<p><b>TIME OF ONSET OF THE PRECIPITATING EVENT OR PROBLEM RELATED TO DETERIORATION</b> <input type="checkbox"/></p> <p>0. Within last 7 days  1. 8 to 14 days ago  2. 15 to 30 days ago  3. 31 to 60 days ago  4. More than 60 days ago  8. No clear precipitating event</p>				
<p><b>SECTION 5: DISCHARGE</b></p>					
1.	<p><b>LAST DAY OF STAY</b></p> <p>Date of discharge</p> <table border="1" style="width: 100%; height: 20px;"> <tr> <td style="width: 25%;"></td> <td style="width: 25%;"></td> <td style="width: 25%;"></td> <td style="width: 25%;"></td> </tr> </table>				
2.	<p><b>RESIDENTIAL / LIVING STATUS AFTER DISCHARGE</b> <input type="checkbox"/></p> <p>1. Private home/apartment/rented room  2. Board and care  3. Assisted living or semi-independent living  4. Mental health residence—e.g., psychiatric group home  5. Group home for persons with physical disability  6. Setting for persons with intellectual disability  7. Psychiatric hospital or unit  8. Homeless (with or without shelter)  9. Long-term care facility (nursing home)  10. Rehabilitation hospital/unit  11. Hospice facility/palliative care unit  12. Acute care hospital  13. Correctional facility  14. Other  15. Deceased</p>				
<p><b>SECTION T: ASSESSMENT INFORMATION</b></p>					
<p><b>SIGNATURE OF PERSON COORDINATING/COMPLETING THE ASSESSMENT</b></p>					
<p><b>DATE ASSESSMENT SIGNED AS COMPLETE</b></p> <table border="1" style="width: 100%; height: 20px;"> <tr> <td style="width: 25%;"></td> <td style="width: 25%;"></td> <td style="width: 25%;"></td> <td style="width: 25%;"></td> </tr> </table>					

## APPENDIX B

### Coding syntax

```
DO IF (I1d = 0 & I1h = 0).
RECODE I1c (0=0) (1 thru 3=1) INTO nil.
END IF.
EXECUTE.
DO IF (I1c >= 1 | I1d >= 1).
RECODE I1h (0=1) (1 thru 3=0) INTO Dementia_only.
END IF.
EXECUTE.
DO IF (I1c = 0 & I1d = 0).
RECODE I1h (0=0) (1 thru 3=2) INTO PD_only.
END IF.
EXECUTE.
DO IF (I1c >= 1 | I1d >= 1).
RECODE I1h (0=0) (1 thru 3=3) INTO Pd_and_dementia.
END IF.
EXECUTE.
```

```
DO IF (nil = 0).
RECODE nil (0=0) INTO four_groups.
END IF.
EXECUTE.
DO IF (Dementia_only = 1).
RECODE Dementia_only (1=1) INTO four_groups.
END IF.
EXECUTE.
DO IF (PD_only = 2).
RECODE PD_only (2=2) INTO four_groups.
END IF.
EXECUTE.
DO IF (Pd_and_dementia = 3).
RECODE Pd_and_dementia (3=3) INTO four_groups.
END IF.
EXECUTE.
```

## APPENDIX C

Logistic regression tables

Table C1. Logistic regression predicting likelihood of carer stress in PDD clients

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
							Lower	Upper
Client age	-0.01	0.01	1.20	1	0.27	0.99	0.97	1.01
Male client	0.26	0.13	3.75	1	0.05	1.30	1.00	1.68
Married	0.37	0.24	2.26	1	0.13	1.44	0.90	2.32
Financial hardship	0.14	0.45	0.10	1	0.75	1.15	0.48	2.77
<b>Carer type (Spouse=ref)</b>			0.14	2	0.93			
Child or child in law	-0.09	0.25	0.14	1	0.71	0.91	0.55	1.50
Other	-0.08	0.35	0.05	1	0.83	0.93	0.47	1.84
Informal care hours in 3 days	0.01	0.00	6.08	1	0.01	1.01	1.00	1.02
Lives with client	0.65	0.22	9.17	1	0.00	1.92	1.26	2.93
Decision Making problem	0.51	0.15	10.82	1	0.00	1.66	1.23	2.25
Short-term memory problem	0.16	0.14	1.36	1	0.24	1.17	0.90	1.54
Procedural memory problem	-0.03	0.17	0.03	1	0.86	0.97	0.70	1.35
Disorganised speech	-0.19	0.49	0.15	1	0.70	0.83	0.32	2.17
Easily distracted	-0.28	0.45	0.39	1	0.53	0.76	0.32	1.81
Daily cognitive fluctuations	0.28	0.34	0.64	1	0.42	1.32	0.67	2.59
Wandering	0.23	0.37	0.41	1	0.52	1.26	0.62	2.60
Verbal abuse	0.27	0.37	0.54	1	0.46	1.32	0.63	2.74
Resists care	0.23	0.31	0.56	1	0.45	1.26	0.69	2.30
Falls	0.24	0.13	3.53	1	0.06	1.27	0.99	1.62
ADL	0.08	0.05	3.29	1	0.07	1.09	0.99	1.19
IADL	0.01	0.01	2.57	1	0.11	1.01	1.00	1.03
DRS	0.19	0.04	30.18	1	0.00	1.21	1.13	1.30
Abnormal thought	0.17	0.34	0.26	1	0.61	1.19	0.61	2.31
Delusions	-0.06	0.30	0.04	1	0.85	0.94	0.52	1.70
Hallucinations	0.35	0.17	4.07	1	0.04	1.42	1.01	2.00
Disturbed sleep	0.28	0.12	4.99	1	0.03	1.32	1.03	1.68
Second carer present	-0.30	0.13	5.51	1	0.02	0.74	0.58	0.95
Lonely	0.11	0.16	0.52	1	0.47	1.12	0.82	1.53
Change in social activities in last 90days	0.30	0.12	5.91	1	0.02	1.35	1.06	1.72
Social contact frequency	-0.03	0.02	1.52	1	0.22	0.97	0.93	1.02

Table C2. Logistic regression predicting likelihood of carer stress in PDD clients

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for Exp(B)	
							Lower	Upper
Client age	0.02	0.02	1.66	1	0.20	1.02	0.99	1.05
Male client	-0.02	0.25	0.01	1	0.94	0.98	0.60	1.60
Married	0.52	0.46	1.28	1	0.26	1.68	0.68	4.14
Financial hardship	-0.62	0.90	0.46	1	0.50	0.54	0.09	3.18
<b>Carer type (Spouse=ref)</b>			1.22	2	0.54			
Child or child in law	-0.18	0.45	0.16	1	0.69	0.83	0.35	2.02
Other	-0.99	0.90	1.21	1	0.27	0.37	0.06	2.16
Informal care hours in 3 days	0.01	0.01	1.59	1	0.21	1.01	1.00	1.02
Lives with client	0.60	0.43	1.95	1	0.16	1.83	0.78	4.27
Decision Making problem	0.42	0.31	1.84	1	0.18	1.52	0.83	2.80
Short-term memory problem	1.06	0.43	6.17	1	0.01	2.88	1.25	6.65
Procedural memory problem	-0.22	0.26	0.67	1	0.41	0.81	0.48	1.35
Disorganised speech	0.98	0.79	1.51	1	0.22	2.65	0.56	12.59
Easily distracted	-1.21	0.78	2.43	1	0.12	0.30	0.07	1.37
Daily cognitive fluctuations	-0.17	0.44	0.14	1	0.71	0.85	0.35	2.02
Wandering	0.59	0.29	4.06	1	0.04	1.81	1.02	3.22
Verbal abuse	0.23	0.34	0.48	1	0.49	1.26	0.65	2.43
Resists care	0.03	0.30	0.01	1	0.93	1.03	0.57	1.86
Falls	0.36	0.21	3.01	1	0.08	1.44	0.95	2.16
ADL	0.03	0.08	0.15	1	0.70	1.03	0.88	1.20
IADL	-0.01	0.02	0.59	1	0.44	0.99	0.96	1.02
DRS	0.11	0.06	3.73	1	0.05	1.11	1.00	1.24
Abnormal thought	0.05	0.35	0.02	1	0.89	1.05	0.53	2.07
Delusions	0.00	0.33	0.00	1	0.99	1.00	0.53	1.91
Hallucinations	0.09	0.22	0.17	1	0.68	1.10	0.71	1.70
Disturbed sleep	0.18	0.21	0.77	1	0.38	1.20	0.80	1.81
Second carer present	-0.43	0.21	4.00	1	0.05	0.65	0.43	0.99
Lonely	0.05	0.28	0.03	1	0.87	1.05	0.60	1.83
Change in social activities in last 90days	0.07	0.20	0.13	1	0.72	1.07	0.72	1.60
Social contact frequency	-0.06	0.04	2.89	1	0.09	0.94	0.88	1.01

Table C3. Logistic regression predicting likelihood of carer stress in AD clients

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
							Lower	Upper
Client age	-0.01	0.00	11.04	1	0.00	0.99	0.99	1.00
Male client	0.29	0.04	43.22	1	0.00	1.34	1.23	1.46
Married	0.00	0.08	0.00	1	0.98	1.00	0.85	1.17
Financial hardship	0.18	0.14	1.59	1	0.21	1.19	0.91	1.57
<b>Carer type (Spouse=ref)</b>			29.48	2	1			
Child or child in law	-0.19	0.08	5.01	1	0.03	0.83	0.70	0.98
Other	-0.56	0.11	25.89	1	0.00	0.57	0.46	0.71
Informal care hours in 3 days	0.01	0.00	37.80	1	1	1.01	1.00	1.01
Lives with client	0.41	0.06	42.50	1	0.00	1.50	1.33	1.69
Decision Making problem	0.49	0.06	64.80	1	1	1.63	1.45	1.84
Short-term memory problem	0.08	0.09	0.70	1	0.40	1.08	0.90	1.29
Procedural memory problem	0.17	0.05	11.33	1	1	1.19	1.07	1.31
Disorganised speech	0.15	0.13	1.29	1	1	1.16	0.90	1.49
Easily distracted	0.18	0.11	2.59	1	0.11	1.20	0.96	1.49
Daily cognitive fluctuations	-0.10	0.10	0.90	1	1	0.91	0.74	1.11
Wandering	0.13	0.06	4.80	1	0.03	1.14	1.01	1.27
Verbal abuse	0.50	0.06	70.13	1	0.00	1.65	1.47	1.86
Resists care	0.29	0.06	25.23	1	0.00	1.34	1.20	1.51
Falls	0.18	0.04	16.65	1	0.00	1.19	1.10	1.30
ADL	-0.08	0.02	18.39	1	0.00	0.93	0.89	0.96
IADL	0.00	0.00	0.02	1	0.88	1.00	0.99	1.00
DRS	0.15	0.01	174.20	1	0.00	1.16	1.13	1.19
Abnormal thought	0.16	0.08	4.17	1	0.04	1.17	1.01	1.37
Delusions	0.27	0.07	13.26	1	0.00	1.30	1.13	1.51
Hallucinations	-0.03	0.07	0.24	1	0.62	0.97	0.84	1.11
Disturbed sleep	0.27	0.04	36.20	1	0.00	1.31	1.20	1.43
Second carer present	-0.12	0.04	7.56	1	1	0.89	0.81	0.97
Lonely	0.16	0.06	7.97	1	0.00	1.17	1.05	1.31
Change in social activities in last 90days	0.15	0.04	13.11	1	1	1.16	1.07	1.26
Social contact frequency	-0.03	0.01	20.41	1	0.00	0.97	0.95	0.98

Table C4. Logistic regression predicting likelihood of carer stress in ND clients

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
							Lower	Upper
Client age	0.00	0.00	0.02	1	0.88	1.00	1.00	1.00
Male client	0.24	0.03	66.57	1	0.00	1.27	1.20	1.34
Married	0.22	0.05	22.56	1	0.00	1.25	1.14	1.36
Financial hardship	0.37	0.07	25.21	1	0.00	1.45	1.26	1.68
<b>Carer type (Spouse=ref)</b>			110.00	2	2			
Child or child in law	0.00	0.05	0.01	1	0.93	1.00	0.90	1.10
Other	-0.50	0.07	54.57	1	0.00	0.61	0.53	0.69
Informal care hours in 3 days	0.01	0.00	162.35	1	0.00	1.01	1.01	1.01
Lives with client	0.52	0.04	179.68	1	0.00	1.68	1.55	1.81
Decision Making problem	0.45	0.04	149.32	1	0.00	1.57	1.46	1.68
Short-term memory problem	0.20	0.03	38.83	1	0.00	1.22	1.15	1.30
Procedural memory problem	0.01	0.04	0.10	1	0.75	1.01	0.94	1.09
Disorganised speech	-0.19	0.10	3.24	1	0.07	0.83	0.67	1.02
Easily distracted	-0.06	0.09	0.50	1	0.48	0.94	0.79	1.12
Daily cognitive fluctuations	0.11	0.08	2.12	1	0.15	1.12	0.96	1.31
Wandering	0.15	0.10	2.31	1	0.13	1.16	0.96	1.41
Verbal abuse	0.83	0.07	152.06	1	0.00	2.28	2.00	2.60
Resists care	0.29	0.06	21.20	1	0.00	1.33	1.18	1.50
Falls	0.16	0.03	34.30	1	0.00	1.18	1.11	1.24
ADL	-0.02	0.01	2.66	1	0.10	0.98	0.96	1.00
IADL	0.02	0.00	202.27	1	0.00	1.02	1.02	1.03
DRS	0.17	0.01	582.64	1	0.00	1.19	1.17	1.21
Abnormal thought	-0.06	0.09	0.38	1	0.54	0.94	0.79	1.13
Delusions	0.23	0.09	5.96	1	0.01	1.26	1.05	1.51
Hallucinations	-0.11	0.07	2.31	1	0.13	0.89	0.77	1.03
Disturbed sleep	0.15	0.03	28.76	1	0.00	1.17	1.10	1.23
Second carer present	-0.15	0.03	26.43	1	0.00	0.86	0.81	0.91
Lonely	0.18	0.03	26.29	1	0.00	1.19	1.11	1.27
Change in social activities in last 90days	0.11	0.03	15.93	1	0.00	1.12	1.06	1.18
Social contact frequency	-0.03	0.01	28.50	1	0.00	0.97	0.96	0.98

