

Ageing Intensifies the Care Needs of Adults Living with Parkinson's Disease and Their Carers

Margaret Giles, PhD\*  
and  
Meghan Thomas, PhD  
Edith Cowan University  
270 Joondalup Drive, Joondalup  
Western Australia 6027

and

Gill Lewin, PhD  
Professor of Ageing,  
Curtin University of Technology  
GPO Box 1987, Bentley  
Western Australia 6487

**Statement of Conflict of interest,**

Margaret Giles, Meghan Thomas and Gill Lewin declare that they have no conflict of interest.

\*Corresponding author:

Dr Margaret Giles

Email: [m.giles@ecu.edu.au](mailto:m.giles@ecu.edu.au)

Telephone: 61 8 6304 5749

Fax: 61 8 6304 5271

## **Abstract**

Parkinson's disease (PD) is the second most common neurological disorder in Australia typically affecting people over the age of 65. Few studies of people living with Parkinson's disease have estimated current hours of home support and unmet needs. In addition no studies have been found that estimate hours of unmet need in terms of functioning or care arrangements or examined whether these estimates differ depending on the viewpoints of carers and the people living with PD whom they care for.

In 2007, we surveyed the home care support needs of adults diagnosed with Parkinson's disease in Western Australia (WA). The survey revealed that adults living with Parkinson's disease prefer, and can be supported with, home care support services in lieu of residential care placement. As expected, required services increased as functioning decreased. In addition, unmet needs were found to be greater for those with carers irrespective of their level of functional dependency. Unmet needs for weekly services, for people that require home support services, are estimated at 38 minutes, 33 minutes, 55 minutes and 47 minutes for personal care, cleaning, social support, and gardening and home maintenance, respectively. The survey also found that most carers and people living with PD agreed that current levels of different types of home care support including nursing were either adequate or insufficient; some carers preferred more services even if the people living with PD were satisfied and some people living with PD wanted more services even if their carers reported needing no extra help. Respite was used by 29% of people living with PD with carers with two thirds wanting more opportunities for respite. Of the 71% of people living with PD with carers who had not used respite, less than half stated that they would like to use respite.

The 2007 survey was followed by interviews with a sample of survey respondents at different stages of their disorder. In the interviews, most of the people living with Parkinson's disease commented that continuing to remain at home depended on the rate of degeneration of their disorder as well as the ability of their carers to continue to care. Most of these people and their carers were living day-to-day with a hope that enough support would be made available if and when they need it. As vocal Baby Boomers age, policymakers would do well to acknowledge the diversity of care needs for people with Parkinson's disease and address the quantum and type of support to meet these needs.

## **Keywords**

Parkinson's disease, home care support services, carers, unmet needs, levels of dependency.

## Introduction

Parkinson's disease (PD) is a chronic, progressive, incurable condition. It typically affects people over the age of 65 years with the prevalence increasing with age (Blackmer, 2009). Symptomatic difficulties, which usually worsen significantly over the course of the disorder (Myers and Chakraborty, 2011), are resting tremor, rigidity, bradykinesia and postural instability (Hall, 2003; Scharlach, 2012). These are not universal symptoms and can affect some people with PD and not others. If present, symptoms may affect some people living with PD acutely and others less so. In addition to potential compromised motor control, people living with PD might also exhibit non-motor symptoms such as cognitive impairment including visuospatial, attentional, executive and memory deficits (Aarsland, Bronnick, and Fladby, 2011: 371; Hely *et al.*, 2008).

Such physical and mental deterioration, albeit often a long period of time, results in a higher percentage of people with PD living in residential care compared with the general population at similar ages (Access Economics, 2007; Porter, Henry, Gray, and Walker, 2010). This is despite most people with PD preferring to continue to live at home even as their support needs increase (Aoun, Kristjanson and Oldham 2006), even up to the time of their death (Porter *et al.* 2010). This is a familiar entreaty in the palliative care literature (see, for example, O'Connor and Pearson 2004).

Given the high prevalence of PD (7 cases per 1,000 population for those over 70 years) and its duration (50% die within 15 years of disease onset) (Blackmer, 2009), enabling people with PD to remain living in their homes would avoid or delay costly institutionalisation (Access Economics, 2007; Porter *et al.*, 2010) and improve their quality of life (Dowding, Shenton, and Salek, 2006). However, with the average age of 70 years for people living with PD and their carers (or 'care-partners' (Bhimani 2014)), the type and amount of home care support provided is critical. This is especially so for most countries who are going to experience significant increases in the ageing population in the not too distant future. For example, one in four people in the United Kingdom (Cracknell, 2010) and Australia (Productivity Commission, 2005) and one in five people in the United States (US Department of Health and Human Services, 2012) will be aged 65 years and over by the middle of the 21<sup>st</sup> century.

In Australia, living at home for the frail aged or disabled is made possible by Federal and State/Territory government funding of a variety of health, disability and aged care services. Such services reduce or delay costly institutionalisation including for people living with PD. The main funded categories of home care support services in Western Australia (WA) at the time of the survey were personal care, cleaning, social support, gardening and home maintenance, and nursing (Fine, 2012). Other services include specialist

care advice such as that provided by a Parkinson's nurse specialist (Parkinson's WA, 2012), physiotherapy, podiatry, occupational therapy, dietetics, speech pathology, respite and transport. These funded services are usually delivered under contract by home care providers including Silver Chain, Perth Home Care, Multiple Sclerosis Society of Western Australia (Inc.), the Neurological Council of Western Australia, and Parkinson's WA (the member support agency).

The government funding contracts often delineate maximum hours or occasions of services per client resulting in clients receiving services which are an approximate rather than a best fit for their needs. In cases where the government funding caps result in insufficient services, the home care providers utilise other funds, available through their own fundraising efforts or from bequests. However, these funds may be subject to waiting lists. Irrespective of funding source, such formal care in the home is thought to be the most financially viable model for aged care (Fine 2012).

In addition to funded services, people living with PD may also require informal care from family and friends. This includes help with those activities of daily living (ADLs) (Collin, Wade, Davies, and Horne, 1988) which are not necessarily covered by funded home support services such as help with making phone calls, with toileting, with visits to the doctor and with shopping. If carers themselves are frail aged, then they may be unable to provide this assistance or only able to provide it in a limited way. Studies that report on unmet care needs include Kristjanson (2004) who found that 22% of people living with PD and 29% of their carers had some (unquantified) unmet need for home care support services and Fine (2012) who summarised that a joint crisis in the provision of informal and formal care has resulted in an emerging care gap.

This paper reports on findings from a quantitative survey and follow-up qualitative interviews for people with PD and their carers from a bigger mixed methods study of adults with neurodegenerative disorders, including PD, in Western Australia in 2006-2008 (Giles and Lewin 2008a). Unlike the Kristjanson (2004) study, this study included seriously ill people living with PD and sampled a broader range of home care service providers. Our hypotheses are that gaps between reported current hours of formal home care support services and perceptions of needed hours of service across different categories of home care support services exist, and that these gaps differ depending on difficulties and functioning of people living with PD and their informal care arrangements.

## **Method**

The study employed a mixed methods design involving a cross-sectional survey (quantitative data) and interviews (qualitative data). Ethics clearance was received from all participating organisations and the survey

and interview instruments were piloted and amended accordingly (Giles and Lewin 2008a). In 2007, the survey was mailed to members of the Parkinson's WA and clients of Silver Chain (the largest community care provider in WA), and other service organisations using member and client mailing lists and achieved a response rate of 54%.

The survey respondents were a sample of clients or members of service provider or support agency mailing lists. A comparison of the age and gender profile of survey respondents and agency members suggested sufficient similarities to assume that the survey results can be generalised to characteristics of overall agency memberships. That is, non-response bias is unlikely. However, people living with PD who were not members of their support agency or receiving services from the main home care service providers were not surveyed. Stephan *et al.* (2012) summarise that such convenience sampling can usefully meet particular study objectives despite potential sample selection bias. As this study was specifically looking at current and needed hours of home care support, the exclusion of some people living with PD may have resulted in a downward bias in total needed hours for the cohort of people living with PD with PD living in WA in 2007. Average hours of needed support and hence average unmet demand may however be unbiased. Nonetheless, it can be argued that people living with PD excluded from mailing lists are more likely to be at the early stage of their disorder where their needs are increasing but they have yet to access care services than they are to be at the later stages when formal care needs and gaps in care services are high.

The survey included questions for the people with PD (Section A), questions about respite for both the people with PD and their carer (Section B), and questions for the carer (Section C). Section A questions asked when respondents first experienced symptoms as well as when they were first diagnosed. Completed surveys from respondents who were yet to be diagnosed at the time of the survey were not included in the analysis. This is consistent with the alternative approach to estimating PD incidence proposed by Foltynie *et al.* (2004) where onset of the disorder is taken from the date of diagnosis rather than the less exact date of first symptoms (page 551). The rationale is that the latter could be confounded by a sub-clinical period of mild and indiscriminate symptoms for which the person living with PD does not seek medical help.

Other questions in Section A referred to living arrangements, housing, and symptoms as well as their abilities to undertake Instrumental Activities of Daily Living (IADL) and Activities of Daily Living (ADL). The IADL questions, such as ability to use the telephone, and the ADL questions, for example ability to shower, were based on Lawton and Brody's (1969) and Barthel's (Collin, Wade, Davies, and Horne, 1988) IADL and ADL scales, respectively. Section A of the survey also had a series of questions asking if the person with PD

received any services from a home care service provider, support agency or local council and if so, how many hours per week for different types of services they currently received and, at that stage, thought they needed. Responses to these questions were used to derive estimates of unmet demand for different types of services.

Section B questions referred to current use of use of respite – frequency and type – as well as anticipated use. In Section C of the survey form, questions for the carer were about the type and amount of support they were giving and the home care support services they might need. These questions mirrored the questions about current and required home care support services in Section A, thereby allowing a comparison of carer and care recipient perspectives on care needs. Questions in this section were to be left unanswered if the respondent with PD had no carer.

The survey instrument allowed both explicit and open-ended responses. Most responses were coded as categorical variables while some responses were included as continuous variables, such as hours of home care services currently received. Open ended questions, such as listing of other medical conditions or disabilities, were subsequently coded categorically, in this case, using ICD-10 (World Health Organisation, 2010). For all other open ended questions, categories of responses were created. The survey was encoded in American Standard Code for Information Interchange (ASCII) format and data were imported into and analysed using STATA Version 9 (StataCorp LP, 1996–2008). A 5% encoding check and cross-tabulations of comparable variables produced few encoding errors or contradictions, respectively. As mentioned earlier, only those respondents who indicated in Section A that they had PD and gave a year of diagnosis ( $n = 361$ ) were included in the data analyses.

A variable for level of dependency was constructed from survey responses as follows. Respondents were asked if they needed any help with any IADL or ADL. A respondent was then classified as Independent if they did not need help with any IADL or ADL. If a respondent received help either occasionally or all the time with any IADL activity and no help for any ADL activity, then they were categorised as having a low level of dependency. Respondents were classified as having a medium level of dependency or a high level of dependency if they received occasional help with any ADL or help all the time with any ADL, respectively. Table 1 summarises the construction of this variable.

The survey asked respondents to indicate (by providing their name and contact telephone number) whether or not they would be available for interview. Subsequently 13 people living with PD were chosen for interview with selection based on ensuring representation of a variety of living arrangements (with and without a carer) and levels of dependency (independent, low, medium and high). Interviews corroborated or updated the

survey data and provided anecdotal accounts of experiences of living with PD or caring for someone with PD, and use of home care support services.

## Results

Descriptive statistics were calculated for all respondents with PD (n = 361). The reported proportions exclude missing values.

The majority of respondents were male (59%) and partnered (74%) with a mean age of 72 years (standard deviation of 9.2 years) at the time of the survey. Four in five respondents were at least 54 years of age when diagnosed with PD. Disease duration ranged from newly diagnosed to 39 years (mean duration of 8.2 years; standard deviation of 6.3). One in five respondents were living outside the metropolitan area in regional and remote Western Australia.

Many respondents had carers (59%) with 67% of carers being female. The average age of carers was 70.1 years (standard deviation of 9.0) with live-in carers being slightly older (mean age of 70.5 years; standard deviation of 8.6) than carers who resided elsewhere (mean age of 58.7 years; standard deviation of 14.8). In the interviews, most of the people living with PD commented that continuing to remain at home depended on the rate of degeneration of their disorder as well as the ability of their carers to continue to care.

*“... depends how healthy mum and dad keep ... it’s hard to know how much, how quick this disease moves ...”* (Keryl, 54 years, mother as carer)

### *Difficulties*

As expected, a high percentage of people with PD reported difficulties that can be attributed to PD: 86% reported experiencing tremors to some degree, most had some limb weakness (71%), 75% had difficulties with their balance with 48% falling at some time, 61% had trouble remembering and 42% were experiencing some level of depression.

*“(PD) is one of the most debilitating diseases there is because it affects every part of your body, you know, ... it’s the mental side of things. Physical is a big thing as it affects your movement and your walking, everything that goes with that.”* (Alice, 71 years, carer for husband, 69 years)

In terms of mobility, 28% of people with PD had no trouble walking and a further 30% had some trouble walking but didn’t use aids. Most of the remaining people with PD were using walking sticks or frames inside and/or outside the home (38%). Few respondents (4%) were immobile, that is they were either bedridden or able to use a wheelchair with limited or no use of their arms.

*“Going out creates problems, restaurants and so forth ... I’m frightened to go out because I need someone there to get me going. I take a wheelchair with me. That’s the worst thing of all ... not knowing how you’re going to get home. You’re stuck somewhere, people think you’re drunk ... start falling ...”* (Barry, 69 years, wife is carer)

People with PD also reported difficulties more common to ageing: 60% had trouble with their eyesight and some with their hearing (42%), 45% reported bladder incontinence, 44% were sensitive to the cold and 32% were suffering with swollen hands and feet. In addition, two thirds of people with PD also reported other health problems including having had heart surgery or having high blood pressure, osteoarthritis, osteoporosis and/or diabetes.

*“... (PD) stops me doing what I want to do ...”* (Adam, 83 years, wife as carer)

#### *Current and unmet needs*

Respondents who reported on services from home care support agencies (n = 94) were asked to state their current hours of service and estimate their needed hours of service. For half of these respondents (n = 45), the current and needed hours of service were the same. That is, there was no unmet need. For other respondents (n = 49), current hours of service were less than needed hours of service for at least one type of home care support service. Figure 1 shows that the most prevalent category of unmet needs for home care support is gardening and home maintenance (on average, half an hour received per week compared with 1.2 hours needed per week - 60% gap) with unmet need for personal care, cleaning and social support averaging 38 minutes per week (13% gap), half an hour per week (33% gap) and about an hour per week (26% gap), respectively.

[Insert Figure 1 here]

*“If I felt that my husband was hardly able to help me with my stuff well I would (need to move into residential care)”* (Beryl, 79 years, lives with husband)

One of the problems with allocating services to people with PD is the episodic nature of their difficulties. This is most often linked to the effectiveness of their medication which enables them to function ‘normally’ at first and then being less able as the medication wears off.

*“Other people usually see her during her well time and they have no idea of the difficulty she’s having at other times ... in a way Robyn’s success in looking good which of course we try to do causes other people not to understand”* (Bern, 62 years, carer for wife, 58 years)

#### *Levels of dependency*

Table 1 shows that one in five survey respondents could be classified as Independent with 4% having carers. Over one in four survey respondents have a high level of dependency and 42% of these have carers. Overall, the proportion of respondents with carers increases as the need for help with daily activities increases.

[Insert Table 1 here]

Levels of dependency correlate with living arrangements, carer characteristics and unmet home care support needs. First, level of dependency and living alone are correlated with the proportion of people with PD living alone declining as functional dependency increases. About half of people with PD who are functionally independent live alone and only 5% of people who have the highest level of dependency live alone.

Second, level of dependency is contingent upon whether or not people with PD have a carer (chi square = 147.7,  $p = 0.000$ ). Hence, about 12% of people who are functionally independent have a carer compared with 91% of people with a high level of dependency. In addition, living alone is also contingent upon whether there is a carer (chi square = 127.4,  $p = 0.000$ ). That is, if a person with PD is living alone, then they are less likely to have a carer; if a person has a carer then they are less likely to be living alone.

For someone with PD, living with someone, whether or not they identify as a carer, can be useful for help with a variety of complicated and/or small tasks.

*“(Even) doing buttons up is a problem.”* (Barry, 69 years, wife is carer)

Finally, the percentage of PD respondents with average unmet needs increases as functional dependency increases. Figure 2 summarises this. For people without carers, the gap in services averages 52 minutes per week, 81 minutes per week and 35 minutes per week for those with low, medium and high levels of dependency, respectively. Most people without carers who have a high level of dependency are unlikely to be living at home, hence those who are able to remain at home are probably well serviced with a smaller gap in home care support services compared with those with a medium level of dependency. For people with carers, the gaps in home support are 2 minutes, 50 minutes and 88 minutes week for those with low, medium and high levels of dependency, respectively.

[Insert Figure 2 here]

Prima facie, the differences in average unmet needs by dependency category using ANOVA are not statistically significant. However, as the standard deviations of average unmet needs are increasing with average gap hours (and increasing dependency), homogeneity of variance was tested using Levene’s test (Brown and Forsythe, 1974). This showed no statistically significant difference between category variances at the 5% significance level ( $W_0 = 1.9086$ ,  $F = 0.1312$ ,  $p = 0.0884$ ,  $df = 6, 86$ ).

The survey data allow a general comparison of the home care support needs from the perspectives of the person living with PD and their carer. Figure 3 presents this for the four main categories of services as well as for nursing. It can be seen that the proportion of agreement differs depending on the type of service. There is most agreement on the need for more gardening and home maintenance help (over 50%) and least agreement on the need for more personal care services (less than 20%). For all categories, some carers would prefer more services even though the person they care for is satisfied with the current level of service.

[Insert Figure 3 here]

### *Respite*

Excluding missing data, 150 carers and people living with PD provided information on their current and expected use of respite. Table 2 shows that half of people living with PD with carers were not accessing respite and were not considering using respite. Of those using respite, 60% wanted more opportunities to use it. Of those not currently using respite, 30% wanted to try it.

[Insert Table 2 here]

In interviews, people with PD and their carers reported mixed reactions to their respite experiences. Both acknowledge staffing issues precluding individual attention.

*“I have been in a nursing home and I find that the nursing care is inadequate for my Parkinson’s condition and ... because of the inadequate care in the nursing home I found that I can do better being cared for in my own home in my own time where I’m not being a restriction to other people and other people being a restriction to me be they patients or nursing staff ... if one was in a nursing home situation, one would expect the staff to be a lot more considerate than they usually are. Admittedly they are up against available time and the numbers of available staff ... there’s always usually a difficulty ...”* (Joseph, 66 years, no carer)

*“When he has respite care, Dr P puts him into the hospital because going into a respite facility isn’t sufficient for him because ... you’re just there without supervision ... tablets (etc) so I feel a bit guilty taking up a hospital bed for him but he should be going in to have that more often”* (wife/carer of Adam, 83 years)

### **Discussion**

Results from this study of what people with PD and their carers think they need in terms of home care support services show that the personal care needs of people with PD were, on average, being met – 87% of needs being met. For cleaning and social support, 67% and 74% of needs were being met, respectively. However, needs for gardening and home maintenance services were less well met – 38% of needs being met. Although the latter may seem a less important category of home care support services, studies of the impact of living environments of the elderly on their quality of life reveal the importance of being close to nature and having gardens available (see, for example, Brereton *et al.*, 2012).

These results are derived from survey questions asked of the people living with PD. Interestingly, the responses from carers to similar questions are not always the same. That is, there are some differences between people living with PD and carers in terms of expressed home care support needs. The reasons for these are likely to be complex. For example, personal care which people with PD are satisfied with but carers would like more assistance with is an intimate service with which people with PD may be uncomfortable if provided by a non-family member. However, because it can require specific skills such as lifting and transferring, carers may prefer trained staff to provide such care. Carers who are elderly or who have their own mobility or health issues may also find the physical demands of providing personal care too onerous. Similarly, people living with PD are on average satisfied with the amount of social support they receive but their carers would like more. This could result from carers feeling socially isolated as they are unable to leave the person they care for and would themselves like some companionship and social interaction.

The finding that people living with PD are less satisfied with the level of nursing and cleaning services they receive than their carers could be explained thus. The person living with PD may be aware of the pressures their carer is under and they see nursing and cleaning as the most legitimate and acceptable way of getting more help. That is, the carers may interpret the person living with PD wanting more help with personal care or social support as a reflection of them not doing enough whereas they might be less likely to take offence at having more help with doing the cleaning.

These possible reasons for differences in the perceived needs of people living with PD and their carers cannot be confirmed by responses to the survey questions. Moreover, the extent to which the differences in expressed needs reflect differences in the reliability of self-reports by people living with PD (Bhimani (2014) and their carers cannot be gauged by the data in this study. Both issues could be investigated in a future study using mixed methods.

For people with PD, residential respite is problematic (Giles and Lewin, 2008b). In WA, all people admitted to residential care homes are firstly required to undergo an assessment of their abilities and needs by a federally funded Aged Care Assessment Team (ACAT). For people with PD, assessment undertaken at a time in the day when the person with PD is functioning well (due to medications) may result in being assigned to low level care for residential respite. However, functioning may fluctuate considerably during the day, so that care needs will go from low care to high care, including needing help with transferring, throughout the day. The assigned respite facility may not, for staffing and other reasons, be able to accommodate the high level of care.

Compounding this issue of fluctuating needs is that the effectiveness of PD medications requires that they be given at precise times throughout the day. This timing has been determined to complement their lifestyle, therefore can impact hugely on their quality of life if not adhered to. At home, the individual or their carer can ensure this. However, in a residential facility, it may be impractical to manage the daily medications for a large number of residents in a timely way. In addition to the issue of the timing of medications, people with PD may have other needs that require a flexibility that routinised care regimes (Sandvoll, Kristoffersen, and Hauge, 2012: 3) in nursing homes cannot logistically provide or afford.

Giles and Lewin (2008b) report that providers argue for different types of respite such as overnight respite in the home. This type of respite would allow the carer to have a good night's sleep whilst the care recipient remains safe, with toileting and other night-time needs met. For example, symptoms of PD can be particularly acute at night. People with PD can have nightmares, act out dreams or call out in the night. They may have altered rapid eye movement sleep behaviour disorder (Boeve, Silber, and Ferman, 2004; Salah Uddin and Jarmi, 2007). They may have lots of physical movements – “loss of normal voluntary muscle atonia” (Salah Uddin and Jarmi, 2007). In addition, often people with PD need toileting during the night (up to eight or nine times) which necessitates help from their carer because of their mobility difficulties. These disruptions to sleep continuity can result in broken sleep for both the person with PD and their carer.

The use of respite services that provide family and friends with care responsibilities with occasional or frequent breaks from the physical and emotional demands of caring is important to the sustainability of care at home. Short breaks such as a few hours can be used by carers to catch up on sleep, go to a movie, play sport or visit a friend. Longer breaks can allow the carer to attend to their or their family's other needs. For example, a female carer of a male with PD living in a regional area used a respite week to travel to the metropolitan area to attend a wedding. For people with PD, short respite in the home or at a day centre can enable them to socialise,

learn how to use new equipment or enjoy a variety of activities such as craft and exercise. Residential respite for a longer period can also enable people with PD and their carers to allay their fears of institutional care (Hall, 2003).

This study significantly extends an earlier study by Kristjanson (2004). First, unlike the earlier study, this study surveyed people with PD at home irrespective of disease stage. Secondly, surveys were mailed to both members of support agencies and clients of various providers thereby widening the population base. Finally, each survey was completed by the people with PD and their carers if they had one. This has enabled analysis of carer and care recipient perspectives finding that there are some disagreements about needs, services and respite. Lyons *et al.* (2002) refer to this as dyadic incongruence and suggest that it can be exacerbated by the use of formal care services. For example, care recipients may resist any or more formal services when carers would welcome them. Our survey results show that this is the case for 61% of people with PD who have carers.

In agreement with other studies (O'Connor and Pearson, 2004), the ability of people with PD to remain living at home, as their disorder progressed, appeared to be conditional on their living arrangements. Since carers of people with PD tend to be the similarly aged spouses of people with PD, PD carers are older on average (70 years) than the typical carer in Australia (48 years) (Access Economics, 2005). A carer's ability to care for the person with PD will be contingent on having their own needs met, especially if they develop their own health issues. Given trends towards fewer long term relationships, fewer children and less community connectedness (Brereton *et al.*, 2012), the proportion of people with PD who have the option of living in the community could be expected to decrease over time. This trend will exacerbate the pressure on residential care waiting lists which will also be affected by the effects of an increasingly ageing population on PD prevalence rates.

There are limitations with this study: questions about clinical needs, medication, disease severity and type of PD were not included in the survey, and respondents are a convenience sample (Dowding *et al.*, 2006). However, the sample is reasonably large (n = 361) suggesting that analyses can provide useful indications of the home care support needs of people with PD. Both the survey and interview data support the conclusion by Aoun *et al.* (2006) that service models for people with neurodegenerative disorders, including PD, should be sufficiently flexible to tailor to individual and specific needs.

### **Conclusions: The challenges of PD for ageing carers**

To reduce or delay costly institutionalisation of people with PD, it is important that appropriate, sufficient and timely home care support be provided. Caring for sick, disabled or frail aged partners, family or

friends can be difficult but rewarding. In cases where caring continues for many years (as is the case with young age onset of PD), the difficulties of caring may be compounded by health and financial issues arising for ageing carers. Often the move from care in the home to residential care follows from a succession of successful periods of respite. Sometimes it results from irreversible on-the-spot decisions that need to be made when there is no Plan B (Bruera, 2006) for when existing care arrangements become insufficient.

*“Those are the sort of things you don’t want to think about ... deal with it when it happens ... if”*

(wife/carer of Adam, aged 83 years)

With the average ages of people living with PD and their carers (about 70 years), the type and amount of home care support provided are critical. This is especially so for most countries which will experience significant increases in their older population cohort. By 2050, one in five (20.9%) US citizens will be over the age of 65 years (U.S. Census Bureau, 2012) primarily reflecting the aging of the baby boom cohort. In Australia, this proportion is projected to rise to one in four by 2044/2045 (Productivity Commission, 2005).

### **Compliance with ethical standards**

Disclosure of potential conflicts of interest

The survey was funded by LotteryWest, the state lottery of WA, as part of a larger project (Grant Ref: 253/20060277) investigating the home support needs of adults living with neurodegenerative disorders.

Informed consent

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

### **References**

Aarsland, D., Bronnick, K., & Fladby, T. (2011). Mild Cognitive Impairment in Parkinson's Disease. *Current Neurology and Neuroscience Reports*, 11, 371-378.

Access Economics. (2005). *The Economic Value of Informal Care*. Report for Carers Australia Canberra, ACT: Access Economics.

Access Economics. (2007). *Living with Parkinson's Disease: Challenges and positive steps for the future*. Canberra, ACT: Access Economics Pty Ltd.

Aoun, S. M., Kristjanson, L., & Oldham, L. (2006). The Challenges and Unmet Needs of People with Neurodegenerative Conditions and Their Carers. *ACCNS Journal for Community Nurses*, 11(1), 17-20.

- Bhimani, R. (2014). Understanding the Burden on Caregivers of People with Parkinson's: A Scoping Review of the Literature. *Rehabilitation Research and Practice*, September.
- Blackmer, J. (2009). Parkinson Disease. *eMedicine*. <http://emedicine.medscape.com/article/312519-overview>. Accessed 25 March, 2013.
- Boeve, B. F., Silber, M. H., & Ferman, T. J. (2004). REM sleep behavior disorder in Parkinson's Disease and dementia with Lewy bodies. *Journal of Geriatric Psychiatry and Neurology*, 17(3), 146-157.
- Brereton, L., Gardiner, C., Gott, M., Ingleton, C., Barnes, S., & Carroll, C. (2012). The hospital environment for end of life care of older adults and their families: an integrative review. *Journal of Advanced Nursing*, 68(5), 981-993.
- Bruera, E. (2006). Process and Content of Decision Making by Advanced Cancer Patients. *Journal of Clinical Oncology*, 24(7), 1029-1030.
- Collin, C., Wade, D. T., Davies, S., & Horne, V. (1988). The Barthel ADL Index: A Reliability Study. *International Disabilities Studies*, 10, 61 - 63.
- Cracknell, R. (2010). *The ageing population*. London, UK: House of Commons Library Research.
- Dowding, C. H., Shenton, C. L., & Salek, S. S. (2006). A Review of the Health-Related Quality of Life and Economic Impact of Parkinson's Disease. *Drugs and Aging*, 23(9), 693-721.
- Fine, M. D. (2012). Employment and Informal Care: Sustaining Paid Work and Caregiving in Community and Home-based Care. *Ageing International*, 37(1), 57-68.
- Foltynie, T., Brayne, C. E. G., Robbins, T. W., & Barker, R. A. (2004). The cognitive ability of an incident cohort of Parkinson's patients in the UK. The CamPaIGN study. *Brain*, 127(3), 550-560.
- Giles, M., & Lewin, G. (2008a). *An Investigation into the Home Support Needs of Adults Living with Multiple Sclerosis, Huntington's, Parkinson's and Motor Neurone Diseases: Client and carer survey results*. Osborne Park: Silver Chain.
- Giles, M., & Lewin, G. (2008b). *An Investigation into the Home Support Needs of Adults Living with Multiple Sclerosis, Huntington's, Parkinson's and Motor Neurone Diseases: Key Issues and Unmet Needs - Health, Allied Health and Service Provider Perspectives*. Osborne Park: Silver Chain.
- Hall, M. I. (2003). The Care Agreement: Attractions and Pitfalls. *Elder Law Review*, 2, 1-9.
- Hely, M.A., Reid, W.G.J., Adena, M.A., Halliday, G.M. & Morris, J.G.L. (2008). The Sydney Multicenter Study of Parkinson's Disease: The Inevitability of Dementia at 20 years. *Movement Disorders*, 23(6), 837-844.
- Kristjanson, L. (2004). *Assessment of the Effectiveness of Australian Models of Palliative Care Delivery in Four Neurodegenerative Disorders*. Perth: Edith Cowan University.
- Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and Instrumental Activities of Daily Living. *Gerontologist*, 9, 179 -186.
- Lyons, K.S., Zarit, S.H., Sayer, A.G. & Whitlatch, C.J. (2002). Caregiving as a Dyadic Process: Perspectives From Caregiver and Receiver. *Journal of Gerontology: PSYCHOLOGICAL SCIENCES*, 57B(3), P195-P204.
- Myers, J., & Chakraborty, A. (2011). Neurodegenerative Disorders. In L. L. Emmanuel & S. L. Librach (Eds.), *Palliative Care: Core Skills and Clinical Competencies* (Second ed., pp. 435-450). St Louis, Missouri: Elsevier.
- O'Connor, M., & Pearson, A. (2004). Ageing in Place - Dying in Place: Competing Discourses for Care of the Dying in Aged Care Policy. *Australian Journal of Advanced Nursing*, 22(2), 32-38.

- Parkinson's WA. (2012). *Clinical Services - Parkinson's Nurse Specialist Service*. Perth, Western Australia.
- Porter, B., Henry, S. R., Gray, W. K., & Walker, R. W. (2010). Care requirements of a prevalent population of people with idiopathic Parkinson's disease. *Age and Ageing*, 39(1), 57-61.
- Productivity Commission. (2005). *Economic Implications of an Ageing Australia: The Prevalence of Disability*. <http://www.pc.gov.au/study/ageing/finalreport/technicalpapers/technicalpaper07.pdf> . Accessed 17 April, 2013.
- Salah Uddin, A. B. M., & Jarmi, T. (2007). REM Sleep Behavior Disorder. *e-medicine*, 11 January.
- Sandvoll, A., Kristoffersen, K., & Hauge, S. (2012). New quality regulations versus established nursing home practice: a qualitative study. *BMC Nursing*, 11(1), 7.
- Scharlach, A. (2012). Creating Aging-Friendly Communities in the United States. *Ageing International*, 37(1), 25-38.
- StataCorp LP. (1996–2008). *Stata/SE software*. College Station, Texas: StataCorp LP.
- Stephan, B. C. M., Wharton, S. B., Simpson, J., Matthews, F. E., Ince, P., & Brayne, C. (2012). The epidemiological neuropathology of dementia and the implications for drug development. *Neurodegenerative Disease Management*, 2(5), 471–482.
- U.S. Census Bureau. (2012). *2012 National Population Projections: Summary Tables*. <http://www.census.gov/population/projections/data/national/2012/summarytables.html>. Accessed 17 March, 2013.
- US Department of Health and Human Services. (2012). *Projected Future Growth of the Older Population*. Washington, DC: Administration on Aging.
- World Health Organisation (2010). *International Classification of Diseases (ICD) Version 10*. Geneva, Switzerland: WHO.

Table 1: Levels of dependency

Levels of dependency	ADL	IADL	% of people living with PD (n = 356*)	% of people living with PD with carers (n = 212)
Independent	No help	No help	19.1	3.8
Low dependency	No help	Some help	26.1	16.0
Medium dependency	Help sometimes with at least one ADL	No help or some help	27.2	38.2
High dependency	Help always with at least one ADL	No help or some help	27.5	42.0

Note: \* Five respondents had incomplete answers to questions from which levels of dependency were derived.

Table 2: Respite needs

Need for respite	No. of people living with PD with carers	%
Use and want more	26	17.3
Use and getting enough	17	11.3
Do not use and want to	32	21.3
Do not use and don't want to	75	50.0
Total	150	100

Figure 1: Average current hours and extra needed hours for people living with PD

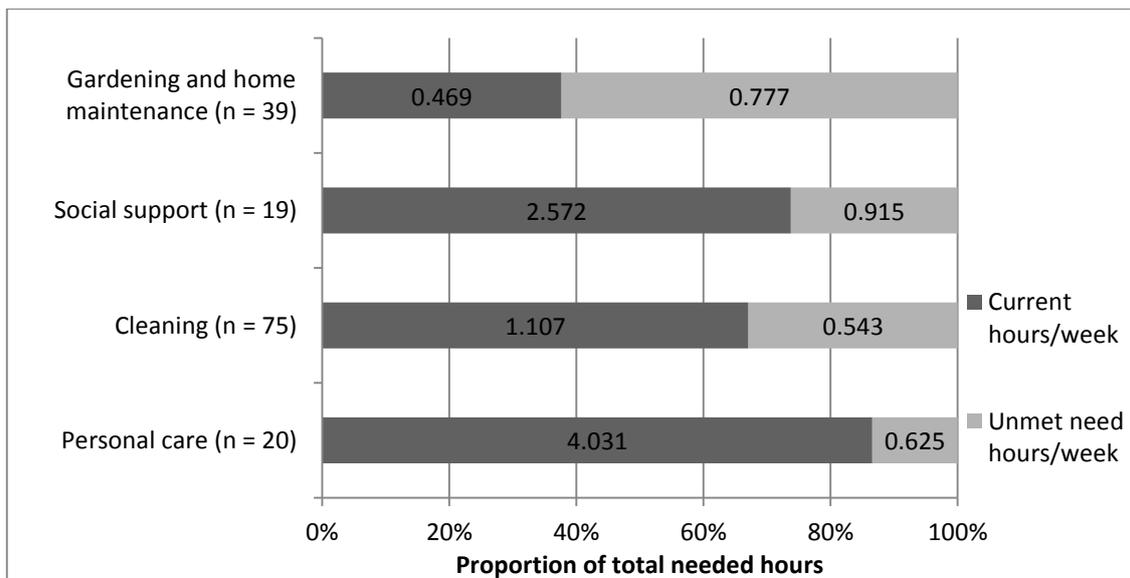


Figure 2: Unmet need for home care support services by levels of dependency

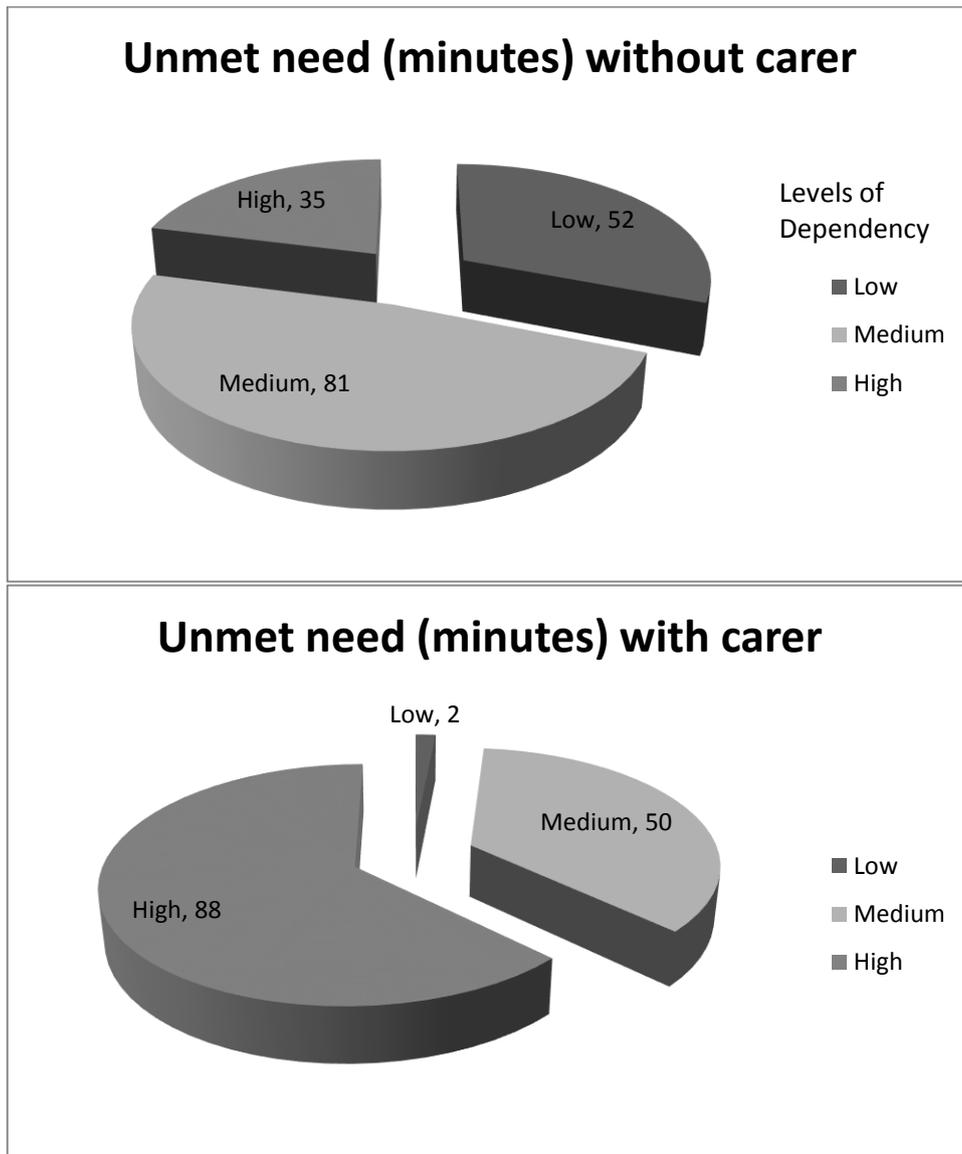


Figure 3: Comparison of expressed home care support needs by people living with PD and their carers

