

The Version of Record of this manuscript has been published and is available in *Aging & Mental Health* (2016) <http://dx.doi.org/10.1080/13607863.2016.1247414>

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Experiences of caring for a family member with Parkinson's disease: A meta-synthesis

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Experiences of caring for a family member with Parkinson's disease: A meta-synthesis

Abstract

Objective: The aim of this qualitative meta-synthesis was to search and then synthesise family caregivers' experiences of providing care to individuals with Parkinson's disease.

Method: A systematic search resulted in the identification of 11 qualitative studies. Noblit and Hare's seven stage approach was used to provide a higher order interpretation of how family caregivers' experienced the effects of taking on a caregiving role.

Results: The process of reciprocal translation resulted in four overarching themes: (1) the need to carry on as usual – *'the caregiver must continue with his life'*; (2) the importance of support in facilitating coping – *'I'm still going back to the support group'*; (3) the difficult balancing act between caregiving and caregiver needs – *'I cannot get sick because I'm a caregiver'*; (4) conflicts in seeking information and knowledge – *'maybe better not to know'*.

Conclusion: The themes reflected different aspects of family caregivers' lives that were affected as a result of caring for a relative diagnosed with PD and these raise challenges for more simplistic theories of family caring and appropriate support structures. The findings also highlight several recommendations for clinical practice.

Keywords: Parkinson's disease, caregiver, caregiving, family.

Parkinson's disease (PD) is a complex, chronic motor neurodegenerative illness (Dyck, 2009), characterised by tremor, rigidity, abnormality of posture and bradykinesia (Razali, Ahmad, Rahman, Midin & Sidi, 2011). In addition to the physical symptoms, individuals can also experience progressive cognitive deterioration (Bhatia & Gupta, 2003) and psychological difficulties such as depression and anxiety (Muzerengi, Contrafatto & Chaudhuri, 2007). Most individuals with PD continue to live at home for many years after the diagnosis (Miller, Berrios & Politynska, 1996) and as activities of daily living become more difficult, family members often take on more informal caregiving tasks (Razali et al., 2011).

As the disease progresses, family caregivers may have to make a series of adaptations to cope with the various physical, cognitive and emotional difficulties that people with PD often experience (Dyck, 2009; Waite, 2000). As symptoms progress, the level of care required may change (O'Reilly, Finnan, Allwright, Smith & Ben-Shlomo, 1996) and this adoption of caring tasks can be physically, psychologically, emotionally and socially demanding (Davey, Wiles, Ashburn & Murphy, 2004). Research from Parkinson's UK, a leading UK charity, suggests that around 90% of family caregivers are partners or spouses (Parkinson's UK, 2009), with a majority spending more than 50 hours a week on caring responsibilities. In the same survey, around a quarter of respondents had been caring for over 10 years; although Parkinson's disease tends to be diagnosed later in life, people with the condition usually have an average lifespan, meaning caring responsibilities can be extended into partners' older age. Perhaps not surprisingly, studies have found that family caregivers' perceived 'burden' and level of depression correlates with the involved relatives' depression levels and quality of life (e.g., Schrag, Hovris, Morley, Quinn & Jahanshahi, 2006), as well as their physical health (e.g., Peters, Fitzpatrick, Doll, Playford & Jenkinson, 2011), indicating how caregiver wellbeing is linked to that of the person with PD.

Consequently, it is important to understand the experiences of family caregivers' who take on caring tasks in order to ensure they receive the necessary support. Although quantitative research has

measured concepts such as carer burden and correlated this with demographical and clinical indices (e.g., Thommessen et al., 2002; Leroi, McDonald, Pantula & Harbishettar, 2012), these studies cannot provide a more holistic account of family caregivers' experiences. In contrast, qualitative studies have allowed researchers to gain a rich understanding of the experience of caregiving in PD and there is now a sufficient corpus for a synthesis to be worthwhile. Such a synthesis should produce 'higher analytic goals' (Sandelowski, Docherty & Emden, 1997, p.366) and provide a level of understanding not accessible by reading each study individually. Other syntheses have been conducted on the family caregiver experience where the partner has a neurodegenerative disease; while these have provided useful insights on the nature of relationship change (e.g., Wadham, Simpson, Rust & Murray, 2015), which have implications for the experience of long term caring more generally, the specific challenges of caring for people with Parkinson's disease does merit more specific attention. Consequently this review provides a meta-synthesis of studies which have examined family caregivers' experiences of providing care for a family member with PD.

Methodology

Searching for studies

The papers selected for inclusion in this meta-synthesis met the following inclusion criteria: (i) the paper was published in English language; (ii) the paper was published in a peer reviewed journal; (iii) the paper involved a study using a specified qualitative method of data collection and analysis; (iv) the paper involved understanding the experience of a family caregiver of an individual with PD. Where a small number of non-family members (e.g., friends or professionals) were included in the papers, these papers were still included as it was considered that this insertion did not detract from the studies' ability to contribute to a meaningful synthesis. Papers were excluded if they solely focused on the experience of the individual with PD or combined the experience of caring for family members with different illnesses, for example, caring for individuals with Alzheimer's and others caring for individuals with PD where experiences were not separated.

Relevant qualitative research papers were identified by conducting a systematic literature search in the databases PsycINFO (searchable years 1989-2014, 'peer reviewed' selected), MEDLINE (searchable years 1977-2014, 'English' selected), CINAHL (searchable years 1994-2014, 'peer reviewed' selected), Academic Search Complete (searchable years 2000-2014, 'peer reviewed' selected) and Web of Science (searchable years 1993-2014). The full-text search terms used to identify potential papers were [experience* OR qualitative OR interview* OR grounded theory OR phenomenolog* OR narrative OR thematic analysis] AND [care* OR caring OR look*] AND [famil* OR relative* OR parent* OR spous* OR partner* OR husband OR wife OR sibling* OR brother OR sister] AND [Parkinson*]. There were no limits set on the date of publication; the search was conducted in March 2014. This database search returned 700 papers (PsycINFO = 110, MEDLINE = 178, CINAHL = 85, Academic Search Complete = 143, Web of Science = 184: see Figure 1). These papers were then reviewed by reading the titles and abstracts, however for those papers where the information provided did not make the suitability clear the full text was read and the inclusion and exclusion criteria applied. In total, 11 papers were identified that met the criteria for inclusion in the current review.

[Figure 1 about here]

Characteristics of the studies

Summaries of the 11 papers are outlined in Table 1. All papers were published between 2000 and 2012. Three studies were conducted in America, two in Northern Ireland and individual studies came from Canada, Australia, Singapore, Sweden, the UK and one international study. The various methods of analysis employed (according to the authors) were phenomenological ($n = 6$), thematic analysis ($n = 2$), grounded theory ($n = 1$), and content analysis ($n = 2$).

[Table 1 about here]

Quality appraisal of selected studies

The Critical Appraisal Skills Programme (CASP, 2013) was used to assess the quality of each paper included in the review. It assesses ten areas relevant to the quality of research such as appropriateness of

methodology and ethical considerations. The initial two questions are designed to screen the papers in terms of there being a clear aim of the research and appropriate methodology to address the research question. The following eight can be summed to create an overall score (score range 8-24). All studies included in the meta-synthesis met these criteria and were subsequently appraised for their quality.

The CASP score was not used as a means of excluding papers. The first author rated the papers then obtained an independent second rating of a selection of the papers, resulting in agreements regarding the quality of the papers. CASP scores for each item ranged from a quality score of 1 to 3, with three being the highest quality and one being the lowest (Duggleby et al., 2010). Findings presented in the current paper are derived from papers of average to good quality (total scores 16-24; see Table 1).

Analysing and synthesising the selected studies

Noblit and Hare's (1988) seven stages of synthesis approach was used in the current meta-synthesis. Although this approach was originally developed for as a review method for ethnographic studies it can also be applied when synthesising different types of qualitative research (Noblit & Hare, 1988). While a number of approaches to qualitative synthesis exist, meta-ethnography was chosen for this review as the number of studies included was relatively small and the focus of interest relatively narrow (Cameron et al., 2003). Moreover, meta-ethnography as a method has been used to review qualitative studies including people with neurodegenerative diseases (Perry-Young, Owen, Kelly, & Owens, 2016) and their caregivers (Hubbard, McLachlan, Forbat, & Munday, 2012; Wadham, Simpson, Rust & Murray, 2015). After identifying the research area and applying the inclusion criteria as discussed above, each paper was read and re-read in order to extract methodological information and the original themes. Themes were compared across papers and as they were similar, reciprocal translation occurred, followed by the synthesis of similar themes and the identification of new ones. Finally overarching themes were constructed. Table 2 indicates the development of the overarching themes.

[Table 2 around here]

Results

The four overarching themes represent different family caregivers' needs and aspects of their lives affected by caring for a relative with PD.

The need to carry on as usual - "the caregiver must continue with his life"

This theme refers to family caregivers' experiences of trying to continue with life as they had prior to their family member receiving a diagnosis of PD. It encompasses: their experience of their relationships with the person and their wider social network; their roles both in and out of the family as well as their inclusion in society, both for themselves and their family member with PD.

Inclusion

Family caregivers described different experiences relating to whether they still felt included in society generally and in specific activities they may have been involved in prior to their family member receiving a diagnosis of PD (Den Oudsten, Lucas-Carrasco, Green & The WHOQOL-DIS Group, 2011; Hudson, Toye & Kristjanson, 2006; Wressle, Engstrand & Granerus, 2007). Some family caregivers reported a decreased level of socialisation which Wressle et al. (2007) interpreted to be due to the family caregiver's 'fatigue and lack of understanding from friends' (p.135). Social isolation is often an inadvertent consequence of caring for people with chronic conditions and it is interesting that the stigma and exclusion often felt by people with a disability can also be felt by caregivers. This could indicate that the contagion theory of physical disability (e.g., Park, Faulkner, & Schaller, 2003), where individuals with a physical disability are actively avoided because of the perceived 'contagiousness' of their impairment, could also be extended to be relevant to those closest to them.

However, while some family caregivers' experiences of inclusion in society were negative, there were also positive examples (Den Oudsten et al., 2011; Habermann, 2000). One family member reported 'most people are very understanding' (Den Oudsten et al., 2011, p.2502) which facilitated inclusion in social events or even more mundane activities such as shopping trips. Moreover, Tan, Williams and Morris (2012) noted that caregivers felt an increase in public awareness would enable more people to understand the disease better. There was a sense that ignorance towards PD had the ability to affect how well caregivers and their relatives were able to continue to engage with life as usual.

Maintaining some independence

Regardless of the nature of their experience, continuing to be included in society in the same manner as they were previously was important to family caregivers. However, due to the increased level of care required by individuals with PD, particularly during later stages, family caregivers struggled to find time away from their caregiving role and when they did this would only be for a short period of time (Abendroth, Lutz & Young, 2010; McLaughlin et al., 2010; Wressle et al., 2007). This was due to factors such as the perceived level of dependency of the person with Parkinson's on the caregiver and feelings of guilt (Hodgson, Garcia & Tyndall, 2004; McLaughlin et al., 2010; Tan et al., 2012). Irrespective of this struggle, caregivers' need to maintain and carry on with their own lives was of clear importance to many (Habermann, 2000; Tan et al., 2012). One caregiver noted "the caregiver must continue with his life or her life. It does not mean life stops when they are caregivers" (Tan et al., 2012, p.2239).

Managing change in roles and relationships

Caregivers also had to manage changes in their roles and daily routines. Wressle et al. (2007) interpreted this in terms of their responsibilities around the home and to their family member. Some family caregivers reported that these role changes conflicted with their previous roles which they then found overwhelming (Hodgson et al., 2004; Tan et al., 2012). Assuming the tasks for which their relative may have previously been responsible (McLaughlin et al., 2010) created additional, and often unwanted, responsibilities. Furthermore, in addition to these newly adopted duties and roles, caregivers also had other family members who required their attention. A challenge was therefore associated with this need to manage competing responsibilities, for example when continuing to care for other dependent family members (Hodgson et al., 2004; Tan et al., 2012).

Receiving a diagnosis appeared to redefine the relationship family caregivers had with their family member with PD. It was apparent that caregivers, in particular spouses, were no longer able to engage in activities together that they had done previously (Den Oudsten et al., 2011; Habermann, 2000). One caregiver noted "there's a lot of things we don't do" (Habermann, 2000, p.1412), highlighting the

reduction in, and frequency of, joint activities due to reasons such as a change in finances, exhaustion, time constraints and mobility problems (Wressle et al., 2007). A reduction in income was generally a result of the individual with PD or their family caregiver having to give up their job (Abendroth et al., 2012; Hudson et al., 2006; McLaughlin et al., 2010). This change in financial resources contributed to limiting activities such as social events and holidays (Den Oudsten et al., 2011), thus affecting social isolation and stress. It also caused increasing strain due to financial worries they had not had prior to caregiving (Abendroth et al., 2012).

Despite these apparent negative changes, Tan et al. (2012) noted that many caregivers also identified positive changes, gaining a sense of satisfaction and improvements in relationships, dispelling the burden labelled rhetoric so common in these types of studies. It also indicates that 'disruptions' in expected biographies (Bury, 1982) need not always be negative. Some family caregivers felt the disease had not affected how they spent their time together, rather it had changed their relationship (Habermann, 2000). There were various opinions on how a diagnosis of PD had affected spousal relationships (Den Oudsten et al., 2011; Habermann, 2000). One caregiver explained "our relationship is better than it ever was" (Habermann, 2000, p.1413) and another noted "he is just a lot more pleasant person to be around" (Hodgson et al., 2004, p.108). In contrast, another explained "thirty years ago, my husband and I were partners, nowadays I am his carer" (Den Oudsten et al., 2011, p.2504). Williamson, Simpson and Murray (2008) also commented on how spousal caregivers struggled to cope with the change in the identity of the family member with PD. Interestingly, it was evident that caring for a spouse with PD changed their relationships, but did so in different ways (Habermann, 2000; Williamson et al, 2008). The majority of respondents were spouses and difficulties in coping with perceived changes in identity seemed to be more pronounced in these spousal relationships.

The importance of support in facilitating coping – "I'm still going back to the support group"

This theme relates to family caregivers' experiences of accessing and receiving support as well as their perceptions of support in order to cope. Availability of support was important to many caregivers in terms of their ability to cope with the caregiving role. However, many family caregivers reported their

experience of support as insufficient and requiring improvement with support being seen to be essential in making the caregiving experience easier (Tan et al., 2012). Support needs were considered to be greatest when the disease was in the advanced stages (Hudson et al., 2006). Numerous caregivers found support groups to be a valuable support system (Hodgson et al., 2004; Hudson et al., 2006; Tan et al., 2012), providing psychosocial support and giving relatives the chance to meet others in a similar position to themselves and share their experiences (Wressle et al., 2007). One caregiver explained “even since my husband passed away; I’m still going back to the support group” (Hudson et al., 2006, p.90). Conversely, others did not find support groups helpful at any stage of the disease trajectory. One caregiver stated “it was the worst thing I could have done” (Hudson et al., 2006, p.90) as it showed them how unwell their relative may become as the disease progresses.

Family support

Additionally, support from other family members was also identified as important in the caregiving experience (Abendroth et al., 2012; Wressle et al., 2007). Wressle et al. (2007) commented on how family caregivers found receiving psychological support from families important, potentially to promote positive well-being and reduce feelings of social isolation. It was also interpreted that without family support, caregivers may not be able to cope and subsequently may have had to explore other residential options for their relative (Abendroth et al., 2012). Where there was a lack of wider family support, this was perceived as frustrating (Hudson et al., 2006), with some caregivers feeling abandoned and unsupported as a result of caring for a family member with PD (Hasson et al., 2010).

Finance and service support

Also of importance was financial support (McLaughlin et al., 2010). Some caregivers were reported as not seeking financial support due to them being unaware of the availability. One caregiver stressed “Benefits! (we) knew nothing about that at all” (McLaughlin et al., 2010, p.180). In some cases financial support was not obtained and people continued struggling with the financial implications of caring for a family member with PD (Hudson et al., 2006; McLaughlin et al., 2010).

Accessible healthcare services were identified as important sources of support with regards to helping caregivers cope (Den Oudsten et al., 2011), especially when the disease progressed (Hudson et al., 2006). Support from healthcare professionals was appreciated across a wide range of challenges – including getting access to other professionals (e.g., physiotherapy), information on new drugs or methods of using medication to avoid ‘off’ periods where function was poor and general advice on navigating the health and social care system. Problems, however, were noted with long waiting times, variable quality of interaction and minimal psychological support (Hasson et al., 2010). Family members felt access to their specialist should be more regular and that there should be more psychological support available, rather than just focussing on medication (Hasson et al., 2010). Some family members believed a more integrated healthcare system would improve services, suggesting different aspects of support could be accessed in the same place (Giles & Miyasaki, 2009; Tan et al., 2012). Furthermore, not only were healthcare services of importance to help the family member support their relative, they were understood to be an important source of direct support for the family member (Hudson et al., 2006).

Having numerous available sources of support was of great importance to family caregivers and without these support structures there was a risk of reduced well-being due to emotional and physical exhaustion, worry and social isolation (Tan et al., 2012). However, it was evident that there were individual differences with regards to the types of support caregivers found useful as within each family unit different tensions and needs were evident.

The difficult balancing act between caregiving and caregiver needs – “I cannot get sick because I’m a caregiver”

Caregiving had numerous effects on people (Abendroth et al., 2010; Hudson et al., 2006; Tan et al., 2012), in particular an emotional impact (Hudson et al., 2010). Family caregivers experienced distress, depression, anxiety and guilt (Hudson et al., 2010; Tan et al., 2012) and for some there was a palpable sense of desperation: “Parkinson’s just destroys your life” (McLaughlin et al., 2010, p.180). Family members found it upsetting to watch their relatives struggle with PD, with family caregivers explaining “the hardest thing is seeing her like this” (Habermann, 2000, p.1411). This perceived change in the

person with PD's identity was understood to lead family caregivers becoming depressed and irritable (Hodgson et al., 2004). Despite this emotional impact, family caregivers continued caring while feeling anxious, stressed and helpless. Caring for their relative was reported to be of greater importance than their own well-being, with family caregivers neglecting their own self-care, putting their relatives' needs before their own (Abendroth et al., 2010; McLaughlin et al., 2010).

Physical effects

Not only was caregiving emotionally exhausting, it was physically exhausting (Habermann, 2000; Hudson et al., 2006; Tan et al., 2012). Furthermore, family caregivers worried about their ability to care for their relative in the future, as the disease progressed, alongside becoming unwell and being unable to care for their relative (Abendroth et al., 2012; Tan et al., 2012; Wressle et al., 2007). This perception about increased impairment being linked to higher levels of caregiver burden does not seem to be supported in other empirical cross-sectional research (e.g., Zarit, Reever & Bach-Peterson, 1980) but clearly this perception was strong among caregivers. Family caregivers did not feel becoming unwell was an option, with one caregiver noting "I'm worried that I will fall sick. I cannot get sick because I'm a caregiver" (Tan et al., 2012, p.2240). This was likely to place further stress on the family caregiver, ultimately resulting in a decline in their own health, with many family members reporting a health-related impact (Hodgson et al., 2004).

Additionally, the need to access respite care was often due to poor caregiver health as caregivers struggled to cope managing their relative's needs (Hasson et al., 2010). It was recognised that respite care was sometimes essential to the well-being of the family caregiver, however they often neglected self-preservation due to not wanting to leave their relative (Hasson et al., 2010). Feelings of guilt often arose when caregivers made time for themselves (Tan et al., 2012). However, self-care was theoretically (although often not practically) recognised as a way to recharge and improve their emotional and physical well-being (Abendroth et al., 2012).

Positive perspectives

Although there appeared to be a predominantly negative emotional impact on family caregivers, there was also a positive perspective (Abendroth et al., 2012; Den Oudsten et al., 2011). Tan et al. (2012) found that many caregivers had adapted well to caregiving and their family bonds had improved since diagnosis. One family member noted “the good thing to come out of this is he has taught me a lot of patience” (Tan et al., 2012, p.2240). ‘Benefit-finding’ is common in people with chronic illness and their carers (e.g., Pakenham, 2005) and is often linked to positive adjustment and is also associated with more adaptive ways of coping.

Abendroth et al. (2012) also identified how a “glass half full or half empty” (p.450) philosophy influenced how family members experienced their role as a caregiver. This is consistent with other research which has identified optimism as an important resource in dealing with stress (Scheier & Carver, 1992). Moreover, family caregivers who adopted a more positive perspective of PD were more likely to cope with the challenges and maintain their own well-being. However, while there were positive experiences, the majority described caring for a family member with PD as a particularly stressful and difficult role, affecting family caregivers’ well-being and quality of life as they tried to find a balance between looking after their relative and self-preservation (Tan et al., 2012).

Seeking information and knowledge – “maybe better not to know”

This theme refers to family caregivers’ experiences of receiving and seeking knowledge and information about PD. It further encompasses the dilemma of deciding how much information family caregivers actually want to know.

Lack of information

Family caregivers generally identified receiving a lack of information after a relative received a diagnosis of PD (Giles & Miyasaki, 2009; McLaughlin et al., 2010). One family caregiver noted “I didn’t get the brochures or anything from the doctors” (Giles & Miyasaki, 2009, p.121). While caring for a relative with PD, family caregivers generally expressed concern that sufficient care and information was not provided subsequent to diagnosis (Hasson et al., 2010; Tan et al., 2012; Williamson et al., 2008). Furthermore, family caregivers were not always made aware of other services they could access and as a

result were left to seek and access their own support and information (Den Oudsten et al., 2011; Hasson et al., 2010, McLaughlin et al., 2010). This led family caregivers to obtain information from sources such as the internet and support groups (McLaughlin et al., 2010; Williamson et al., 2008). However, sources such as the internet were not always helpful, with one family caregiver noting “I made the mistake of going online” (McLaughlin et al., 2010, p.122), causing increasing confusion and worry. Additionally, many family caregivers felt their family doctors, while highly valued, did not have sufficient in-depth knowledge about the disease (Hasson et al., 2010; McLaughlin et al., 2010).

Furthermore, Williamson et al. (2008) noted how caregivers had not been informed by healthcare professionals about the potential psychotic symptoms than can occur in people with PD. This contributed to family caregivers feeling confused and overwhelmed, with a lack of understanding affecting their ability to cope. When they did see a healthcare professional, some caregivers felt they were not provided with information about how severe the illness could become. One caregiver explained “they don't tell you” (Williamson et al., 2008, p.586), while it was highlighted that being made aware of potential psychotic symptoms would have been helpful.

Need for more information

It was identified that family caregivers wanted more information to be available regarding the management of PD (Tan et al., 2012). Abendroth et al. (2012) interpreted family caregivers' seeking knowledge as a way to reduce their anxiety about caring for a family member with PD. Having the information they wanted about PD provided them with a feeling of empowerment and a sense of being able to cope (Hodgson et al., 2004). Family members further described seeking knowledge by making comparisons with others and accepting the situation they found themselves in (Hodgson et al., 2004; Williamson et al., 2008). One family caregiver described “I'd like to know how other people cope” (Williamson et al., 2008, p.587) as a way of checking if they were doing the best for their family member compared to others. Obtaining information, by making comparisons to people in a more difficult situation, reduced their distress and enabled them to feel more able to cope (Williamson et al., 2008).

Interestingly, while family caregivers felt it was important to be provided with information regarding PD, it was also noted that they were not sure about how much information they wanted (Giles & Miyasaki, 2009; McLaughlin et al., 2010). Reasons for this were not being able to cope with knowing how the disease progresses and subsequently becoming depressed, or being uncomfortable about the potential prognosis the information may imply (Giles & Miyasaki, 2009; McLaughlin et al, 2010). Highlighting this, one caregiver said it “maybe better not to know” (Giles & Miyasaki, 2009, p.123). It is possible that attempting to reduce anxiety had the potential to have the opposite effect. Although there is a decision to be made about how much information to seek, the majority of family caregivers felt that knowing what to expect and understanding the disease more would enable them to provide better care for their family member. Therefore, access to information would support family caregivers in their role caring for their relative (Hasson et al., 2010). While the need for tailored information for individuals with a chronic illness and their carers has been recognised for some time (e.g., Mills & Sullivan, 1999), it is clear that practice in this area is still significantly lagging behind theoretical knowledge.

Discussion

The synthesis of 11 qualitative studies on the experiences of caring for a family member with PD allowed the construction of four overarching themes. The four themes draw attention to the physical, psychological and emotional effects of caregiving, family caregivers' perception of healthcare services and how caring for a relative changed many aspects of their lives. This meta-synthesis highlights the importance of the role of the family caregiver and the need to ensure they are supported in order to care for their relative while maintaining their own well-being. While all the themes are linked and are complementary, an overall tentative model of the family caregiver experience could be proposed. The need to provide care is foremost, influencing family caregivers' decisions about their own life and the sustained delivery of what they consider their responsibilities to their loved one. Indeed, family caregivers' own needs are addressed mostly from the needs of their relative, with even their own self-care carried out from the more overarching perceived need to continue to provide care for their loved one. However the sustained delivery of that care is influenced by factors which can easily go awry – i.e.

changes in level of help from support networks or the accrual of unhelpful information. These factors can have significant effects on the family caregivers' ability to provide care given that the continued provision of care is so delicately balanced as a result of cumulative and sustained stress experienced.. Indeed, relatively small disturbances in the caregivers' situation could cause noticeable difficulties in both their ability to provide care and their confidence in being able to provide it in the longer term.

Clinical Implications

One of the most well-replicated findings within health research is that support from family, friends and wider healthcare services is important in facilitating coping with a long-term illness. However, the utility of social support has been shown to depend on what is expected and how it is perceived by the recipient (Simpson, Haines, Lekwuwa, Wardle & Crawford, 2006), rather than a cruder measure of 'how much' is available. This nuanced relationship between psychological well-being and social support is also relevant to family members caring for a relative with PD. This is congruent with findings from other studies with different patient groups (e.g., in Wuest, Ericson, Stern and Irwin's, 2001, study of caregivers of individuals with Alzheimer's disease). It is therefore important that families, friends and services work with the caregiver to ensure they are being supported in a way that meets their needs.

Similarly, it was highlighted by Wuest et al. (2001) how when support was considered inadequate, this was often due to others' avoidance and this was understood as members of the wider social network feeling uncomfortable around the affected individual. Increasing public awareness may reduce people's anxieties around interacting with people with PD and their family members and subsequently increase the well-being and inclusion of all affected. However, it is clear that disablist attitudes - although of a perhaps more subtle nature - are still common (Deal, 2007) and tackling the effects of 'psycho-emotional disablism' (Thomas, 1999) – i.e. the negative psychological effects of societal-level oppressive attitudes – is a challenge at a societal level but also in terms of providing effective psychological support (Simpson, McMillan & Reeve, 2013; Simpson & Thomas, 2015).

As well as societal interventions or campaigns, there is also the opportunity for therapeutic assistance on an individual level when distress is more marked. In terms of psychological therapies then

the indication that family caregivers - understandably – are often worried about future challenges (such as increased physical impairment) suggests that techniques aimed at grounding experience in the present (e.g., mindfulness-based approaches; Kabat Zinn & Hanh, 2009) might be useful (see also Garlovsky, Overton & Simpson, 2016). The importance of encouraging an optimistic outlook, and one which contrasts with the burden-laden narrative so often used within medical care, is also important (Hogstel, Curry & Walker, 2005). This is not to deny that the experience is challenging but it can also reveal positive facets.

Furthermore, the findings suggested that family caregivers struggled to balance their role caring for their relative with attending to their own needs. Respite care, while not favoured by all, should be increasingly available to promote self-preservation and well-being among family caregivers. Interestingly, Strang, Haughey, Gerdner and Teel (1999) found that dementia caregivers needed to feel it was acceptable to seek respite and that, often, their commitment to caregiving acted as a barrier to this. Receiving respite, however, led to them feeling better and more able to deal with the demands of caregiving (Strang et al., 1999). Furthermore, a survey conducted by the Parkinson's UK (2008) demonstrated that the physical and mental health, in particular stress and fatigue, had deteriorated in over half of PD caregivers since commencing the role. Hence, family caregivers may also require support to feel less guilt about receiving respite in order to improve their physical and mental health.

It is important to compare these findings with those of other reviews of the experiences of family caregivers of people with neurodegenerative diseases to try and identify the more unique factors of the Parkinson's caregiver experience. For example, Aoun et al.'s review of the caregivers of people with motor neurone disease indicated similar concerns about the lack of information available and gaps in what were considered essential services. However, the more accelerated decline in people with motor neurone disease also created more specific, acute challenges whereas in Parkinson's the difficulties were more long-term and therefore the psychological effects were also different. Corry and While (2008)'s review of the caregiver experience in multiple sclerosis also revealed concerns about the lack of support and the difficulties coping with the varied reactions of friends and family; moreover, positive changes in

the relationship and in individual caregivers (such as increased patience) as a result of their new role were also noted. However, a wider range of psychological difficulties which had to be coped with was not noted in this review, for example the development of psychotic symptoms.

In conclusion, the identification of similarities and differences between family caregivers of people with different neurodegenerative conditions has important implications for our understandings – and responses – to their needs. For specific issues, for example increasing cognitive impairment, reviews have suggested a similarity of experience and similar needs across conditions (Grose, Frost, Richardson, & Skirton, 2013). However, the totality of the family caregiver experience can only be adequately explored by specific studies as some issues are less common and therefore could be missed in more overarching approaches. Consequently, our approach to understanding the complexity of the family caregiver experience in specific conditions can be theoretically informed by other relevant research but must also be supplemented by more condition-specific research.

References

- *Abendroth, M., Lutz, B. J., & Young, M. E. (2012). Family caregivers' decision process to institutionalize persons with Parkinson's disease: A grounded theory study. *International Journal of Nursing Studies, 49*, 445-454. doi: 10.1016/j.ijnurstu.2011.10.003.
- Aoun, S. M., Bentley, B., Funk, L., Toye, C., Grande, G., & Stajduhar, K. J. (2013). A 10-year literature review of family caregiving for motor neurone disease: moving from caregiver burden studies to palliative care interventions. *Palliative medicine, 27*(5), 437-446.
- Bhatia, S., & Gupta, A. (2003). Impairments in activities of daily living in Parkinson's disease: Implications for management. *NeuroRehabilitation, 18*, 209-214. Retrieved from PsycINFO database.

- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4, 167-182.
DOI: 10.1111/1467-9566.ep11339939
- Campbell, R., Pound, P., Pope, C., Britten, N., Pill, R., Morgan, M., & Donovan, J. (2003). Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science & Medicine*, 56(4), 671-684.
- CASP UK (2013). Critical Appraisal Skills Programme (CASP): Making sense of evidence. Better Value Healthcare Ltd. Retrieved from
http://media.wix.com/ugd/dded87_951541699e9edc71ce66c9bac4734c69.pdf
- Corry, M., & While, A. (2009). The needs of carers of people with multiple sclerosis: a literature review. *Scandinavian Journal of Caring Sciences*, 23(3), 569-588. doi: 10.1111/j.1471-6712.2008.00645.x
- Davey, C., Wiles, R., Ashburn, A., & Murphy, C. (2004). Falling in Parkinson's disease: The impact on informal caregivers. *Disability and Rehabilitation*, 26, 1360-1366. doi:
10.1080/09638280400000195.
- Deal, M. (2007). Aversive disablism: Subtle prejudice toward disabled people. *Disability & Society*, 22, 93-107. doi: 10.1080/09687590601056667
- *Den Oudsten, B. L., Lucas-Carrasco, R., Green, A. M., & The WHOQOL-DIS group. (2011). Perceptions of persons with Parkinson's disease, family and professionals on quality of life: an international focus group study. *Disability and Rehabilitation*, 33, 2490-2508. doi:
10.3109/09638288.2011.575527.
- Dyck, C. (2009). Who cares for the caregiver? *Parkinsonism and Related Disorders*, 15, S118-S121. doi:
10.1016/S1353-8020(09)70796-5.
- Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C., & Williams, A. (2010). Metasynthesis of the hope experiences of family caregivers of persons with chronic illness. *Qualitative Health Research*, 20, 148-158. doi: 10.1177/1049732309358329.

- Garlovsky, J. K., Overton, P. G., & Simpson, J. (2016). Psychological predictors of anxiety and depression in Parkinson's disease: a systematic review. *Journal of Clinical Psychology*
- *Giles, S. & Miyasaki, J. (2009). Palliative stage Parkinson's disease: Patient and family experiences of health-care services. *Palliative Medicine*, 23, 120-125. doi: 10.1177/0269216308100773.
- Grose, J., Frost, J., Richardson, J., & Skirton, H. (2013). Using meta-ethnography to understand the emotional impact of caring for people with increasing cognitive impairment. *Nursing & health sciences*, 15(1), 113-123.
- *Habermann, B. (2000). Spousal perspective of Parkinson's disease in middle life. *Journal of Advanced Nursing*, 31, 1409-1415. doi: 10.1046/j.1365-2648.2000.01457.x.
- *Hasson, F., Kernohan, W.G., McLaughlin, M., Waldron, M., McLaughlin, D., Chambers, H., & Cochrane, B. (2010). An exploration into the palliative and end-of-life experiences of carers of people with Parkinson's disease. *Palliative Medicine*, 24, 731-736. doi: 10.1177/0269216310371414.
- *Hodgson, J., Garcia, K., & Tyndall, L. (2004). Parkinson's disease and the couple relationship: A qualitative analysis. *Family Systems & Health*, 22, 101-118. doi: 10.1037/1091-7527.22.1.101.
- Hogstel, M. O., Curry, L. C., & Walker, C. (2005). Caring for older adults: The benefits of informal family caregiving. *Journal of Theory Construction & Testing*, 9, 55.
- Hubbard, G., McLachlan, K., Forbat, L., & Munday, D. (2012). Recognition by family members that relatives with neurodegenerative disease are likely to die within a year: A meta-ethnography. *Palliative medicine*, 26(2), 108-122.
- *Hudson, P.L., Toye, C., & Kristjanson, L. J. (2006). Would people with Parkinson's disease benefit from palliative care? *Palliative Medicine*, 20, 87-94. doi: 10.1191/0269216306pm1108oa.
- Kabat-Zinn, J., & Hanh, T. N. (2009). *Full catastrophe living: Using the wisdom of your body and mind to face stress, pain, and illness*. Delta.

- Leroi, I., McDonald, K., Pantula, H., & Harbishettar, V. (2012). Cognitive impairment in Parkinson disease: impact on quality of life, disability, and caregiver burden. *Journal of Geriatric Psychiatry and Neurology*, 0891988712464823. doi: 10.1177/0891988712464823
- *McLaughlin, D., Hasson, F., Kernohan, W. G., Waldron, M., McLaughlin, M., Cochrane, B., & Chambers, H. (2010). Living and coping with Parkinson's disease: Perceptions of informal carers. *Palliative Medicine*, 25, 177-182. doi: 10.1177/0269216310385604.
- Miller, E., Berrios, G. E., & Politynska, B. E. (1996). Caring for someone with Parkinson's disease: Factors that contribute to distress. *International Journal of Geriatric Psychiatry*, 11, 263-268. doi: 10.1002/(SICI)1099-1166(199603)11:3<263::AID-GPS316>3.0.CO;2-P.
- Mills, M. E., & Sullivan, K. (1999). The importance of information giving for patients newly diagnosed with cancer: a review of the literature. *Journal of Clinical Nursing*, 8, 631-642. doi: 10.1046/j.1365-2702.1999.00296.x
- Muzerengi, S., Contrafatto, D., & Chauduri, K. R. (2007). Non-motor symptoms: Identification and management. *Parkinsonism and Related Disorders*, 13, S450-S456. doi:10.1016/S1353-8020(08)70048-8.
- Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesising qualitative studies*. Newbury Park, CA: Sage.
- O'Reilly, F., Finnan, F., Allwright, S., Smith, G.D., & Ben-Shlomo, Y. (1996). The effects of caring for a spouse with Parkinson's disease on social, psychological and physical well-being. *British Journal of General Practice*, 46 (410), 507-512. Retrieved from Web of Science database.
- Pakenham, K. I. (2005). The positive impact of multiple sclerosis (MS) on carers: associations between carer benefit finding and positive and negative adjustment domains. *Disability and Rehabilitation*, 27, 985-997. doi: 10.1080/09638280500052583

- Park, J. H., Faulkner, J., & Schaller, M. (2003). Evolved disease-avoidance processes and contemporary anti-social behavior: Prejudicial attitudes and avoidance of people with physical disabilities. *Journal of Nonverbal Behavior*, 27, 65-87. doi: 10.1023/A:1023910408854
- Parkinson's Disease Society (2008). *Life with Parkinson's today: Room for improvement*. London: Parkinson's Disease Society of the UK.
- Perry-Young, L., Owen, G., Kelly, S., & Owens, C. (2016). How people come to recognise a problem and seek medical help for a person showing early signs of dementia: A systematic review and meta-ethnography. *Dementia*, 1471301215626889.
- Peters, M., Fitzpatrick, R., Doll, H., Playford, D., & Jenkinson, C. (2011). Does self-reported well-being of patients with Parkinson's disease influence caregiver strain and quality of life? *Parkinsonism and Related Disorders*, 17, 348-352. doi: 10.1016/j.parkreldis.2011.02.009
- Razali, R., Ahmad, F., Rahman, F. N. A., Midin, M., & Sidi, H. (2011). Burden of care among caregivers of patients with Parkinson's disease: A cross-sectional study. *Clinical Neurology and Neurosurgery*, 113, 639-643. doi: 10.1016/j.clineuro.2011.05.008.
- Sandelowski, M., Docherty, S., & Emden, C. (1997). Qualitative meta-synthesis: issues and techniques. *Research in Nursing and Health*, 20, 365-37. doi: 10.1002/(SICI)1098-240x(199708)20:4<365::AID-NUR9>3.0.CO;2-E.
- Scheier, M. F., & Carver, C. S. (1992). Effects of optimism on psychological and physical well-being: Theoretical overview and empirical update. *Cognitive therapy and research*, 16, 201-228. doi: 10.1007/BF01173489
- Schrag, A., Hovris, A., Morley, D., Quinn, N., & Jahanshahi, M. (2006). Caregiver-burden in Parkinson's disease is closely associated with psychiatric symptoms, falls and disability. *Parkinsonism and Related Disorders*, 12, 35-41. doi: 10.1016/j.parkreldis.2005.06.011.

- Simpson, J., Haines, K., Lekwuwa, G., Wardle, J., & Crawford, T. (2006). Social support and psychological outcome in people with Parkinson's disease: Evidence for a specific pattern of associations. *British Journal of Clinical Psychology, 45*, 585-590. doi: 10.1348/014466506X96490.
- Simpson, J., McMillan, H., & Reeve, D. (2013). Reformulating psychological difficulties in people with Parkinson's disease: The potential of a social relational approach to disablism. *Parkinson's Disease, 2013*. doi: <http://dx.doi.org/10.1155/2013/608562>
- Simpson, J., & Thomas, C. (2015). Clinical psychology and disability studies: Bridging the disciplinary divide on mental health and disability. *Disability and rehabilitation, 37*, 1299-1304. doi: 10.3109/09638288.2014.961656
- Strang, V. R., Haughey, M., Gerdner, L. A., & Teel, C. S. (1999). Respite - a coping strategy for family caregivers. *Western Journal of Nursing Research, 21*, 450-471. doi: 10.1177/019394599902100403.
- *Tan, S.B., Williams, A.F., & Morris, M.E. (2012). Experiences of caregivers of people with Parkinson's disease in Singapore: a qualitative analysis. *Journal of Clinical Nursing, 21*, 2235-2246. doi: 10.1111/j.1365-2702.2012.04146.x.
- Thomas, C. (1999). *Female forms: Experiencing and understanding disability*. Buckingham: McGraw-Hill Education.
- Thommessen, B., Aarsland, D., Braekhus, A., Oksengaard, A.R., Engedal, K., & Laake, K. (2002). The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson's disease. *International Journal of Geriatric Psychiatry, 17*, 78-84. doi: 10.1002/gps.524.
- Wadham, O., Simpson, J., Rust, J., & Murray, C. (2016). Couples' shared experiences of dementia: a meta-synthesis of the impact upon relationships and couplehood. *Aging & mental health, 20*(5), 463-473.
- Waite, L.M. (2000). Accommodating Parkinson's disease: A review of the perspective of the caregiver and the Parkinsonian. *Loss, Grief and Care, 8*, 173-187. doi: 10.1300/J132v08n03_30.

- *Williamson, C., Simpson, J., & Murray, C.D. (2008). Caregivers' experiences of caring for a husband with Parkinson's disease and psychotic symptoms. *Social Science & Medicine*, 67, 583-589. doi: 10.1016/j.socscimed.2008.04.014.
- *Wressle, E., Engstrand, C., & Granerus, A. (2007). Living with Parkinson's disease: Elderly patients' and relatives' perspective on daily living. *Australian Occupational Therapy Journal*, 54, 131-139. doi: 10.1111/j.1440-1630.2006.00610.x.
- Wuest, J., Ericson, P.K., Stern, P. N., & Irwin, G. W. Jr. (2001). Connected and disconnected support: The impact on the caregiving process in Alzheimer's disease. *Health Care for Women International*, 22, 115-130. doi: 10.1080/073993301300003117.
- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist*, 20, 649-655. doi: 10.1093/geront/20.6.649

Note: Papers following * were included in the meta-synthesis.