



Care Alliance Ireland

The National Network of Voluntary
Organisations for Family Carers

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Parkinson's Association of Ireland

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Care Alliance Ireland and The Parkinson's Association of Ireland

The Caring Reality of Family Carers:

***An exploration of the health status of Family Carers of
people with Parkinson's disease***

June 2010

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Information on the Research Partners

Care Alliance Ireland

Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers. We support organisations in their direct work of supporting Family Carers all over Ireland. We also provide information, education and training, regarding the needs of Family Carers; we carry out research relating to Family Carers, and promote inter agency collaboration.

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The Parkinsons Association of Ireland

The Parkinsons Association of Ireland is a registered charity, based in Dublin, with branches throughout the country. Our aim is to assist those with Parkinson's, their families, their carers, health professionals and interested others by offering support, a listening ear and information on any aspect of living with Parkinson's.

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Glossary of Terms

Family Carer: Defined in the Census 2006 questionnaire as ‘someone who provides regular, unpaid personal help for a friend or family member with a long-term illness, health problem or disability’ (CSO, 2006)

Parkinson’s disease: a chronic and progressive degenerative disease of the brain that impairs motor control, speech and other functions (Jankovic, 2008).

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- Finally, a special word of thanks goes to the 20 Family Carers who agreed to participate, giving up their precious time in sharing their personal experiences. Without their voices, this piece of research would not have been possible.

Abstract

The contribution made by Family Carers is crucial in enabling sick, disabled and older people to remain in the home. However, many Carers are forced to provide care to family members while being inadequately supported in their role. This research sought to develop a greater understanding of the health status of Family Carers in Ireland. A random sample of 20 Family Carers of people with Parkinson's disease participated in a series of qualitative semi-structured interviews.

It was found that the role of the Family Carer was both physically and emotionally demanding, particularly as the person's condition deteriorated and the caring needs intensified. Providing care had powerful physical impacts with significant changes to daily routines noted. High blood pressure, tiredness, lack of physical energy, back problems and arthritis were seen as consequences of caring. As a result of the physical demands of caring, feelings of loneliness, anxiety and depression were all expressed. Providing care also resulted in significant limitations to personal interests and hobbies.

Current periods of respite and state provided home care support were viewed as inadequate by many. Experiences of support from healthcare professionals differed greatly. Family members' support had an important social inclusion aspect. Current levels of financial assistance were seen as insufficient in meeting the needs of Family Carers. Support received by various non-government organisations (NGOs) was seen as highly beneficial. However, joint support meetings for both Family Carer and care recipient were also problematic. A training programme for Family Carers was singled out as a crucial intervention that would assist Family Carers in building up the necessary physical and emotional skills for providing care to a person with Parkinson's disease, thus impacting positively on their health status.

Foreword from Chairperson of Care Alliance Ireland

We in Care Alliance Ireland are delighted to be working with the Parkinsons Association of Ireland in delivering this important piece of research that successfully gives the reader a picture of the reality of caring for someone with Parkinsons.

The issues faced by Family Carers, and in this case mostly partners of those with Parkinsons, are told in way that reflects the reality as well as the love and commitment shown to their loved ones.

This research, the first of its kind in Ireland, will add to our understanding of the caring role played by thousands of families affected by Parkinsons throughout Ireland.

I am delighted that following an extensive peer review process this research will be presented at the 5th International Carers Conference in July 2010

Care Alliance Ireland and The Parkinsons Association of Ireland are both committed to supporting Family Carers in their respective roles as an inclusive alliance and as a condition specific advocacy organisation.

A handwritten signature in black ink, appearing to read 'Colum Conway', with a stylized flourish at the end.

Colum Conway

Chair

Care Alliance Ireland.

June 2010

Executive Summary

Introduction

Caring in Ireland has traditionally existed predominately in the private sphere of the home, reflecting a residualist state response. The health of Family Carers has also been given low priority by the Government even though it is vital for the sustainability of informal care-giving.

The Care Alliance Ireland's (2008) quantitative survey of the health status of Family Carers *The Health Status of Family Carers in receipt of the Carers' Allowance* developed an initial understanding of the relationship between family caring and health in an Irish context. It was therefore felt that it was vital to build on this work; specifically through a qualitative piece of work which aimed to look more closely at the mediating factors for Family Carers' health and well-being. The timing of this piece of research is key; against the backdrop of the publication of a National Carers' Strategy in Ireland being postponed. Additionally, family as a caring unit in Irish society is currently in a period of uncertain change due to a range of factors such as changing demographics and the current economic slowdown.

Through this qualitative piece of research, up to date illustrative information will be made available on the health and well-being of a specific group of Family Carers in Ireland; Family Carers of people with Parkinson's disease. Family Carers of people with this specific condition were chosen following a decision taken to undertake this piece of research in collaboration with the Parkinson's Association of Ireland. The estimated prevalence of individuals with Parkinson's disease in Ireland is over 7,000. It is therefore reasonable to expect that Family Carers of such people represent a sizeable sub-group within the 161,000 Family Carers identified in Census 2006. In addition, the literature review suggests that peer-reviewed qualitative research on the experiences of this group of Family Carers to date is quite limited.

Aims and objectives of the research project

The overall aim of this research project was to explore the health status of a specific group of Family Carers. For the purposes of this research, Family Carers were defined as family members who provide physical and/or social care to a family member with Parkinson's disease in the home.

The specific objectives of this study were as follows:

- To explore Family Carers' perceptions of factors which impact on their health
- To explore Family Carers' needs in relation to factors impacting on their health
- To explore with Family Carers any interventions they could identify which would contribute to their health status given their particular circumstances

Research project design

Participant profile

Participants were recruited by the Parkinson's Association of Ireland through their extensive database of members, specifically targeting two geographical areas. 20 one-to-one interviews were conducted with Family Carers currently caring for a person with Parkinson's disease. Nearly three quarters of those interviewed were female and two thirds were aged 65 years plus.

Data collection

All interviews took place at a time and place most convenient to participants. Interviews were semi-structured in nature, with the assistance of an interview guide. Demographic information on participants was also gathered.

Data analysis

Once interview recordings were professionally transcribed, emerging themes and codes were identified through the extensive process of thematic analysis.

Findings

Following extensive data analysis, four main themes emerged. Numerous commonalities can be found with the findings of this research and those of the Care Alliance Ireland (2008) study and other work carried out in the area to date. Each theme is summarised below.

The experience of the Family Carer

The physical demands and associated responsibilities of the caring role were identified and reflected the severity of the condition. The emotional assistance which participants provided in the role of Family Carer was also detailed. The physical aspects of the role intensified as the condition gradually worsened over time. In addition, the level of physical assistance required could vary dramatically on a day to day basis. Newer Family Carers understood that their role would change over time. Indeed, they viewed caring for a person with Parkinson's disease as a long term role.

Carers' feelings towards caring differed. There was a sense of expectation associated with providing care that related to pre-existing family relationships and roles. However, this sense of 'duty' was not easy for some, leading to feelings of resentment. At the same time, the option of residential care at this time was not considered.

Specific aspects of caring for a person with Parkinson's disease were seen as challenging. Assisting with personal care was hard for some. Changes to individual personality and behaviour as a result of Parkinson's disease were also difficult in some instances. The gradual decline in the person's condition resulted in a physically demanding role and the need for a constant presence. Providing night time care was both upsetting and frustrating at times.

A range of coping techniques used by Family Carers was identified, such as time to self, the ability to undertake personal interests, taking exercise, contact with friends and the presence of support.

For many in this study, caring for a person with Parkinson's disease led to major changes in the relationships that had existed between the caregiver and care recipient. For instance, changes to the person's personality and behaviour were a source of annoyance. In several instances, the person with Parkinson's had also been diagnosed with a secondary condition such as dementia. Where the person's condition entailed extremely high physical assistance, the relationship, while loving, consisted primarily of providing physical care, with limited reciprocity. Allowing the person to remain at home was emphasised by participants when asked what their contribution to overall care was.

The impact of caring

In general, participants' lives before caring had entailed time to self in order to pursue personal interests, with no need to plan in advance. There was a sense of loss for what life had previously been like, prior to undertaking the role of Family Carer. The impact of providing care to a person with Parkinson's disease was found to be multi-dimensional. In stark contrast to life before caring, for many participants nearly all aspects of their life were affected. Providing care had powerful physical, emotional, social and positive impacts, depending on the severity of the condition.

For many, the roles and responsibilities of providing care were both physically demanding and challenging, in particular the night time aspect. As the condition deteriorated, there was a gradual need to be constantly there. A considerable number of Family Carers noted significant changes to their daily routines. Some carers were no longer in a position to continue working outside the home while providing care. However, several continued in this dual role.

Physical aspects of the Family Carers' health and well-being were highlighted. High blood pressure, tiredness, lack of physical energy, back problems and arthritis were all conditions attributed to the constant physical role and high level of manual assistance required in providing care. Lack of time to access necessary medical treatment for themselves was another issue brought up by several Family Carers. Some carers had themselves encountered life threatening physical health conditions prior to undertaking the caring role. Many expressed worry about what would happen to the person with Parkinson's disease in the event that the Family Carer became unwell.

Providing care for a person with Parkinson's disease had a strong impact on the emotional health of many in this study. Feelings of frustration, unhappiness and loneliness were all expressed as a result of the physical demands of the caring role. Periods of depression were also highlighted by Family Carers. There was an expectation on the Family Carer to be 'healthy', leading them to conceal their true feelings and/or health status from others. Feelings of anxiety and concern were commonly expressed, with the care recipient constantly being on the Family Carer's mind. There was uncertainty surrounding their ability to continue to provide care in the home in the future as the condition continued to deteriorate.

There was a significant social impact associated with providing care to a person with Parkinson's disease. Time to self and the ability to undertake personal hobbies or interests were considerably limited and/or adjusted in many instances, leading to feelings of loneliness. Friendships with significant others were seen as an important way of preserving the now restricted time to self.

While the focus of much discussion was on the negative impact of family caring, positive aspects of the role were also highlighted. For instance, several participants believed that they had become closer to the person with Parkinson's disease as a result of providing care and it had had a beneficial influence on their relationship.

Support

Multiple sources of support for the role of Family Carer were identified, falling under the sub-themes of formal, informal and financial support. The provision and levels of support received had an impact on the overall caring experience. Access to respite and day care services were necessary in order to give a short break to Family Carers. However, existing respite services were seen as inadequate. As a result of the care recipient's wishes, several Family Carers received little or no respite. A sense of guilt on receiving respite was also conveyed. Home-based support through paid care workers was another important way by which Family Carers could gain a temporary break and take part in leisure and recreation or indeed just attend to daily chores such as shopping.

At the same time, issues regarding the inadequacy of current periods of home-based support were also highlighted. Indeed, several had sought additional home-based support through paid carers in the private sector due to these inadequacies. The findings showed diverse experiences in support received from healthcare professionals. Many were in receipt of little or no support from their Public Health Nurse. Overall, Family Carers had a good relationship with their GP but lack of support from GPs was also cited as a source of tension. In contrast, support received from other healthcare professionals such as Occupational Therapists was welcomed and seen as beneficial. Further exploration of Family Carers' relationships with healthcare professionals is warranted as it was not within the remit of this study.

Problems in accessing information on entitlements to supports for Family Carers were raised. Newer carers believed that they were still finding their way through the system. However, there was a wish not to seek formal assistance in some instances.

Informal support from family members was highly valued, although levels varied. The presence of other family members also gave Family Carers a short break and allowed them to take part in activities outside of their caring role. When Family Carers were not in good health, many depended on family members to provide care to the person with Parkinson's disease. On the other hand, feelings of sadness and isolation when other family members were not present were mentioned. A lack of understanding of the needs of the Family Carer by other family members was also an issue. A fear of burdening family members led some carers to find it difficult to ask for assistance.

Support received by various NGOs was viewed as highly beneficial and a crucial way of accessing information, both on Family Carer and condition-specific issues. While attendance at support meetings was seen as a way of gaining knowledge, it also had an important social aspect and was a way of meeting other people in similar situations. Nonetheless a number of gaps were highlighted. The distance to travel to support meetings was an issue. Joint support meetings for both Family Carer and care recipient were also problematic. While a support group exclusively for Family Carers was viewed as a possible solution, the need to have someone present to care for the person with Parkinson's disease was a source of concern.

Levels of financial assistance available through the state were condemned. The contribution made by Family Carers was seen as deserving of adequate recognition from the state. Due to the major deficiencies in current state support, some carers had begun saving for future needs as the person's condition continued to deteriorate.

Needs and interventions

A range of possible interventions was outlined that could be put in place to contribute to the overall health status of Family Carers. Time to self was a crucial way of giving Family Carers a break from the role, and in so doing maintaining their own health and well-being. There were a number of ways by which this could be achieved, such as support from other family members, respite and day care services and home-based support. Taking regular exercise was another mechanism used by some carers to have a positive impact on their own health.

A support group exclusively for Family Carers was identified as an intervention that would be beneficial, as a way of exchanging information with fellow carers and also from a social perspective.

A training programme for Family Carers was singled out as a crucial intervention that would assist participants in their role and, in so doing, have a positive impact on their health status. The role of Family Carer continued to change and the level of physical assistance required intensified, as the condition of the person with Parkinson's disease gradually worsened. Acquiring the skills necessary to deal with the emotional aspects associated with providing care was also viewed as extremely important.

Several Family Carers did not think about their own needs or identified what in fact they were, while others believed that the interventions outlined above would prove vital in the future as the person's condition gradually deteriorated.

Key recommendations

1. Put in place conditions necessary for Family Carers to receive regular and sufficient amounts of rest and time to self. Efficient respite services and home-based support targeted at both the needs of the Family Carer and care recipient have a significant role to play in making sure that Family Carers receive regular and sufficient amounts of rest, thus enabling them to continue in their role and having a positive health impact.
2. Introduce a full assessment of Family Carers' needs. There is an urgent need to recognise and address the needs of Family Carers in their own right, alongside those of the care recipient, in assessing care needs and allocation of care services. This would help maintain the Family Carers' health and support them in their role. It is also important that the changing needs of the Family Carer are taken into consideration, as their role may intensify dramatically as the condition of the care recipient deteriorates.

3. Improvement of informal support mechanisms available to Family Carers. It is essential that the NGO sector work collaboratively in the provision of support services to Family Carers. For instance, working in partnership in the area of condition-specific training for Family Carers and in the area of condition-specific carer support groups in order to maximise Family Carers' knowledge and skill base.
4. Introduction of a health promotion programme for Family Carers. It is crucial that Family Carers are encouraged to look after their own health needs. One way in which this could be achieved is through a nationwide, comprehensive, annual check-up for all Family Carers, with equal emphasis given to both the physical and emotional health aspects of caring.
5. Introduction of a public awareness campaign. There is an urgent need to improve awareness, understanding and recognition of Family Carers among the general public through a media campaign at national, regional and local levels.
6. Make education, information awareness and training of healthcare professionals in issues relevant to Family Carers' health a key priority. It is essential that all healthcare professionals have a comprehensive understanding of the role (and changing role) of the Family Carer in order to adequately address their needs.
7. Establishment of an independent Family Carer 24 hour help line. There is an urgent need for an adequately funded and independent help line that Family Carers can access at any time of the day or night in a confidential manner.
8. Provide adequate services to support the health needs of Family Carers in the post-caring phase. It is essential that adequate support measures are put in place in order to improve the lives of Family Carers when their caring has ended, as the physical and emotional health consequences of caring may leave some Family Carers with serious difficulties coping with life after care, particularly for those who may have been caring for several years.

9. All policy steps taken to support the health of Family Carers should be proactive rather than reactive. It is crucial that steps are taken to plan for the future support and health needs of Family Carers, particularly as the demands of the role intensify as the care recipient's condition gradually worsens.

Chapter 1: Introduction

1.1 Introduction

This chapter introduces the background to the study, outlines the study aims and objectives and gives a brief overview of existing literature available on Family Carers' health and also on Parkinson's disease.

1.2 Background to study: setting the context

Caring in Ireland has traditionally existed predominately in the private sphere of the home, reflecting a residualist state response. The health of Family Carers has also been given low priority even though it is vital for the sustainability of informal caregiving. It is difficult to pinpoint the exact number of Family Carers in Ireland. The 2006 Census figures suggest that there are in the region of 161, 000 Family Carers in the Republic of Ireland. The 2006 Census also identified 41,000 full-time Family Carers. This means that the care recipient requires full-time care and attention. In addition, many Family Carers cannot leave the home unless another person is present to take over their caring duties. In short, caring is driven by necessity rather than choice (Carers Strategy Consultation Group, 2008).

The Care Alliance Ireland's (2008) quantitative survey of the health status of Family Carers *The Health Status of Family Carers in receipt of the Carers' Allowance* developed an initial understanding of the relationship between family caring and health in an Irish context. It was therefore felt that it was vital to build on this work; specifically through a qualitative piece of work which aimed to look more closely at the mediating factors for Family Carers' health and well-being.

It is important for the purposes of this research that health was conceptualised in a holistic manner and that physical and emotional aspects of health were given equal consideration. Indeed the World Health Organisation's (1946) definition of health was taken into account in the conceptual framework of health used for this research project:

"Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."

However, as issues with this definition have been identified, the definition of health under the WHO Ottawa Charter for Health Promotion (1986) was also considered appropriate:

“Health is a resource for everyday life, not the objective of living. Health is a positive concept emphasising social and personal resources, as well as physical capacities.”

The timing of this piece of research is key; against the backdrop of the publication of a National Carers’ Strategy being postponed. It was envisaged that the development of a National Carers’ Strategy would provide a framework for the future support of Family Carers in Ireland. Additionally, family as a caring unit in Irish society is currently in a period of uncertain change due to a range of factors, such as changing demographics and the current economic slowdown. Indeed, population projections show that the Irish population will age dramatically over the coming years; this will also lead to a rise in disability, and in turn there will be a greater demand for Family Carers. It is forecast that the percentage of the population over 65 years will rise almost one-fifth by 2036 (equivalent to 1.24 million) compared with 11% in 2006 (462,000) (CSO, 2008).

By projecting the population of those with a disability who are resident in the home, it is estimated there will be an increase in demand by 2021 of over 40,000 carers, with over 25,000 extra required by 2016. This represents a 28% and 17% increase on the 2006 demand for carers respectively. This will result in a population of carers in excess of 200,000 by 2021 (Carers Association, 2009:35). It is therefore essential for Family Carers to be adequately supported in their role while at the same time recognising that Family Carers are also people with their own individual needs. In order to do this effectively, it is vital that we gain an understanding of the extent of the impact caregiving has on the Family Carers’ health and the factors that affect it.

It is proposed that through this qualitative piece of research, up to date illustrative information will be made available on the health and well-being of a specific group of family carers in Ireland. In addition, a voice will be given to the statistics of the quantitative piece of work already undertaken. Questionnaires generally comprise a set of closed questions, usually only allowing pre-defined responses. Qualitative techniques encourage free, spontaneous responses among participants, allowing rich and meaningful data to be gathered.

Family Carers of people with Parkinson's disease have been chosen as the target group for this research project. Family Carers of people with this specific condition were chosen following a decision taken to undertake this piece of research in collaboration with the Parkinson's Association of Ireland. It is estimated that there are over 7,000 people with the condition in Ireland (www.parkinsons.ie). It is therefore reasonable to expect that Family Carers of such people represent a sizeable sub-group within the 161,000 Family Carers identified in Census 2006 (CSO, 2007). In addition, the literature review suggests that peer-reviewed qualitative research on the experiences of this group of Family Carers to date is quite limited.

Parkinson's disease is a progressive neurological condition affecting movements such as walking, talking and writing. Parkinson's occurs as result of a loss of nerve cells in the part of the brain known as the *substantia nigra*. The mean age of onset is approximately 60 years of age, with the incidence and prevalence generally increasing with age. Four main features characterise Parkinson's disease: resting tremor (shaking back and forth when the limb is relaxed); bradykinesia (slowness of movement); rigidity (stiffness, or resistance of the limb to passive movement when the limb is relaxed) and postural instability (poor balance). Other common signs include shuffling gait, stooped posture, difficulty with fine co-ordinated movements, and micrographia (small handwriting). Non-motor symptoms of the disease include sleep disorders, fatigue, sexual dysfunction, sensory symptoms, autonomic dysfunction, cognitive abnormalities and mood disorders (Hauser et al, 2006). Indeed, depression has been identified as a principal determinant of quality of life in Parkinson's disease (Schrag et al, 2000). More recent literature refers to depression as often pre-existing a diagnosis of Parkinson's and estimates vary on incidence in people with Parkinson's from 7% to 76% (Veazey et al, 2005).

There is evidence that co-morbidity with other neuro-degenerative disorders such as dementia can occur with Parkinson's disease. For instance, Aarsland et al (2005) undertook a systematic review of previous studies on the prevalence of dementia in Parkinson's disease. They found that 24 to 31% of Parkinson's patients had dementia, and that 3 to 4% of the dementia in the population would be due to Parkinson's disease.

1.3 Study aims and objectives

The overall aim of this research project was to explore the health status of a specific group of Family Carers. For the purposes of this research, Family Carers were defined as family members who provide physical and/or social care to a family member with Parkinson's disease in the home.

The specific objectives of this study were as follows:

- To explore Family Carers' perceptions of factors which impact on their health
- To explore Family Carers' needs in relation to factors impacting on their health
- To explore with Family Carers any interventions they could identify which would contribute to their health status given their particular circumstances

1.4 Existing literature on Family Carers' health and Parkinson's disease

As part of the 2008 Care Alliance Ireland study, an extensive review of relevant literature was undertaken (Care Alliance Ireland, 2008). The following sections give a brief overview of the current body of existing research on the health of Family Carers.

Research on the health of Family Carers in Ireland is limited. International evidence is much more comprehensive. For instance, Singleton et al (2002) found that Family Carers are three times more likely to report ill-health than the non-carer population. A high risk of depression and stress was found among carers in the UK (Boden 2002, Carers UK 2006). Cummins (2007) found that carers who looked after frail, disabled or mentally ill relatives suffered extraordinary rates of depression and had the lowest level of well-being of any group in society. Additional risk factors that impact on the poor mental health and vitality of carers of a person with a disability were; greater levels of financial pressure, lower levels of support and worse family functioning, according to Edwards and Higgins' (2009) study. Indeed, carers in this study were found to have significantly worse mental health and vitality and higher rates of depression than the general population.

Following analysis of data from the British Household Panel Survey, Hirst (2005) found that heavily involved carers over long periods of time had raised levels of distress. In addition, both the periods immediately following the caring role being assumed and when caring ended had the most pronounced negative effect on the psychological well-being of heavily involved carers.

Scholfield et al (1998) found higher rates of self-reported ill-health and use of medication, more negative effects, and less life satisfaction and perceived social support, among carers than among non-caring women. In Australia, O'Connell (2003) noted that carers were unable to participate in social and health types of activities, due to the burden of care with its difficult and worrying responsibilities. Three quarters of carers identified in this survey suffered from various health problems such as arthritis, high blood pressure and impaired mobility. In a survey of over 5,600 carers undertaken by Carers UK (2007), 71% of respondents believed that health problems affected their ability to care. Pinquart and Sorensen (2007) found that higher age, lower socio-economic status, and lower levels of informal support were related to poorer health among caregivers.

Research in Ireland has shown that caring for an individual in the home can take a toll on the family carer's mental, emotional and physical health, with high levels of burden (O'Donoghue, 2003; O'Connor and Ruddle, 1998; Blackwell et al, 1992;). Research carried out by Lane et al on behalf of the South Eastern Health Board (2000) found that while the vast majority of carers in their study rated their emotional health as having been very good or good before becoming a carer, there was a significant fall in these ratings once the role of carer was assumed. O'Shea (2000) noted that over two-thirds of carers interviewed in his study expressed difficulty in making ends meet and were therefore likely to have suffered some sort of financial strain as a result of their caring responsibilities. In a 2004 report published by the Equality Authority, Cullen et al (2004:p10) argue that:

“caring responsibilities may preclude the fulfilment of a full social life. Indeed, a number of studies have shown that caring can take a toll on the carer's mental, emotional and physical health. Many carers have their own chronic health problems or disabilities.”

The most extensive piece of Irish research to date examining the health status of Family Carers was undertaken by Care Alliance Ireland (2008) *The Health Status of Family Carers in receipt of the Carers' Allowance*. The aim of this research was to quantify the reported health of a random sample of 2,834 Family Carers in receipt of a state carer payment when compared in part to the national non-carer population of the SLÁN 2002 Survey. It was found that, in comparison to the general population, Family Carers who responded (n=1,413) were less likely to report themselves in excellent or very good health. No significant difference was found between carers and the general population in terms of satisfaction with health, but carers did present a considerably less positive picture of quality of life in comparison to the general population.

Carers also reported comparatively high levels of depression, back pain and anxiety. Negative aspects associated with family caring included restricted leisure hours and a high risk of exposure to stress, emotional strain and social isolation. The extent of limitation posed by caring on leisure and recreation appeared to be a key factor both in the likelihood of health suffering due to caring and likelihood of low quality of life for carers.

In relation to the specific health experiences of Family Carers of people with Parkinson's disease, a number of international studies have been undertaken, that illustrate high levels of distress. A significant association between carer burden (CB) and health-related quality of life (HRQoL) was found among Parkinson's carers by Martinez-Martin et al (2007). The main predictors of CB were caregivers' psychological well-being; patients' mood and clinical aspects of Parkinson's disease such as disability and severity; and the HRQoL of patients and caregivers.

Caregiver and patient quality of life were found to be closely linked in Parkinson's disease in a study by Schrag et al (2006). They found that the caregiver-burden increased with increasing disability and symptoms of Parkinson's disease, particularly with mental health problems such as depression, hallucinations or confusion, and with falls. Aarsland et al (1999) found that caregivers of people of Parkinson's disease and in particular spouses, had more severe depression and a higher proportion reported tiredness, sadness and less satisfaction with life when compared with healthy elderly subjects. Mental symptoms of parkinsonian patients were the most consistent and powerful predictors of caregiver distress. Berry and Murphy (1995) explored the relationship between well-being in carers and the disease stage of Parkinson's. The carer's own health was paralleled with the increasingly weakening physical functioning of their partner with Parkinson's disease; carers' social functioning declined with the increase in care needs. Carers' social, psychological and financial well-being was also associated with length of marriage and length of education.

In Ireland, a large scale quantitative study by O'Reilly et al (1996) sought to investigate whether caring for a partner with Parkinson's disease was associated with a worsening social, psychological and physical well-being when compared to people with partners who did not have Parkinson's disease. Carer spouses were found to have slightly worse social, psychological and physical profiles. For social outcomes, increasing care provision was associated with fewer contacts, outings and holidays. For psychological and physical measures, carers providing a lot of care experienced worsened health.

Upon conducting an extensive review of relevant literature on the experiences of providing care to people with Parkinson's disease, Harris et al (2003) made the following conclusions: the well-being of carers was likely to be higher than that of the person with Parkinson's disease. However, carer burden was linked with the severity of Parkinson's. Indeed, perceived patient control over symptoms was associated with carer well-being and less carer burden.

The largest UK survey of people with Parkinson's and their carers was undertaken by the Parkinson's Disease Society (2008), with over 3,000 responses from carers. Providing care to a person with Parkinson's disease was found to have an impact on the physical or mental health of just over half of carers. Of those, nearly nine out of ten carers reported stress or anxiety. Fatigue was an issue for 69% of carers. 61% had problems with sleep. Periods of mild depression were experienced by 49%. Backache, high blood pressure and difficulty concentrating were other physical and mental health effects referred to by participants in the study.

1.5 Conclusion

This research report is seeking to undertake a careful and in-depth investigation on the overall health and well-being of a specific group of Family Carers. In so doing, it is anticipated that the findings will form part of an emerging and larger research agenda on Family Carers, both nationally and internationally. It is hoped that the real beneficiaries of this research will be Family Carers themselves, as the findings will act as a tool to inform policymakers and service providers of future policy development and change needed in order to improve the overall situation of Family Carers.

The following chapters of the research project outline the research methodology, present and discuss the main findings, and conclude by giving recommendations for policy and of future research needed.

Chapter 2: Research Methodology

2.1 Introduction

This chapter outlines the methodology used to conduct this research project. A profile of participants and the sample method used are described. Stages in the collection and analysis of data are outlined. Ethical issues that were important during the study are considered, as are potential limitations.

2.2 Study design

This research project was a small scale study that employed a qualitative methodology in order to gain insights into the experiences and perceptions of a specific group of Family Carers' health status, namely those who provided care to people with Parkinson's disease. The study involved semi-structured one-to-one interviews with Family Carers. The research question that informed the project was: How do Family Carers perceive their own health status?

2.3 Inclusion and exclusion criteria

A list of accepted standards was used in considering the inclusion and exclusion of individuals in this research project and both are outlined below.

The following inclusion criteria were in place for study participants:

- Provided physical and/or social care to a person with Parkinson's disease in the home
- Understood the purpose and process of the research project
- Willingly volunteered to participate in the research project

The following exclusion criteria were in place for study participants:

- Did not provide physical and/or social care to a person with Parkinson's disease in the home
- Did not understand the purpose and process of the research project
- Unwilling or unable to participate in the research project

2.4 Sample

It was proposed to identify 20 Family Carers of people with Parkinson's disease through random sampling. According to Marshall (1996:522): "*An appropriate sample size for a qualitative study is one that adequately answers the research question*" Determining an adequate size ultimately lay with the judgment of the researcher and the quality of information being gathered. In practice, the number of participants required became clearer as the research project progressed and as new themes stopped emerging from the data (i.e. data saturation) (Marshall, 1996). In collaboration with the Parkinson's Association of Ireland (PAI), potential participants were recruited for this study. PAI has an extensive database which documents its members – both people with Parkinson's disease and their Family Carers. Initially, the plan was to focus on one specific geographical area within Ireland with an urban and rural mix. However, potential participants were slow to respond. The focus was then broadened to encompass individuals from a second geographical area.

The recruitment process involved three phases:

1. PAI, acting as a gatekeeper, forwarded letters of invitation to people with Parkinson's disease asking each to nominate a Family Carer to participate in the research project. These letters also included information sheets on the research project, contact details of the researcher, consent forms for information purposes, reply slips and stamped addressed envelopes for the Family Carer. This process was continued until such time as the researcher had an adequate number of participants. Over 50 individuals were contacted and invited to participate. (See Appendix 1 for a copy of the information leaflet and Appendix 2 for a copy of the consent form).
2. Upon receiving reply slips, the researcher contacted Family Carers via telephone to discuss their potential participation, discuss any concerns they may have had and organise to meet at a time and venue most convenient for them, should they wish to participate.
3. At the time of meeting each participant, the researcher revisited the information sheet and consent form and dealt with any concerns that the potential participant had before seeking consent.

2.5 Data collection

Qualitative one-to-one interviews were undertaken. Each was semi-structured in nature, with the assistance of an interview guide (Appendix 3). The interview guide was composed following consultation with a group of Family Carers, identified through a carer forum.¹ Relevant literature on Family Carers was also taken into consideration.

Demographic information on the participants was also gathered before interviews began (Appendix 4). Through completing the demographic sheets, important background information, such as age, gender, location, relationship with care recipient, current and past employment status, hours of care provided, level of care provided and longevity of caring, was gathered from participants. Participants were not asked about their own income and/or finances as it was felt that this could be problematic. For instance, questions of this nature could be perceived as too probing and could in fact risk compromising the engagement of participants in the research project. All demographic information collected was coded and inserted onto Microsoft Excel for analysis purposes. Each interview began following the completion of the demographic information sheets.

Interviews with participants lasted on average 40 minutes. Each interview was recorded, with participants giving permission to do so during the consent process. However, due to technical difficulties, two interviews were not fully recorded. The researcher kept field notes for each interview. The objective of the interviews was to draw out the experiences of the participant in a relaxed and informal manner. Interviews took place at a time and place most convenient to participants. Many Family Carers requested the interview to take place in the home, while in several cases participants chose to meet the researcher at a neutral venue (for example a hotel, coffee shop).

¹ The researcher met with a group of over 50 Family Carers in the north of the Republic of Ireland in November 2008, after seeking permission from the HSE Carers Development Officer for the area. The researcher brainstormed with the group on any ideas/ possible questions that they felt would be useful to ask when interviewing Family Carers. It was felt that through the active involvement of Family Carers in the compiling of an interview guide, the high levels of knowledge and expertise built up in the role of Family Carer were thus acknowledged.

Several broad themes were considered in the interview guide (e.g. affect of caring on life, feelings as Family Carer, health of Family Carer, support, future) along with possible probing questions. However, the overall course of each interview was also guided by the replies and reactions of the individual participant. Those interviews conducted at a later stage were also based on the initial themes appearing in the preliminary analysis of the early interviews.

2.6 Profile of participants

20 interviews were conducted with Family Carers currently caring for a person with Parkinson's disease. Table 2.1 provides an overview of the socio-demographic profile of study participants. Most Family Carers interviewed were female (n = 14), replicating the gender dimension and pattern of Family Caring in Ireland. The majority of Family Carers were in the 65+ age category. Eighteen of the 20 participants were married; equivalent to 90%. The remaining 10% fell into the divorced/separated category. Just over one half were living in an urban location (55%), while 45% were living in a rural location.

The majority of participants were wives of the care recipient (n = 13), with six individuals identifying themselves as husband and one individual as daughter. All Family Carers were living with the care recipient. The composition of nineteen out of twenty households was Family Carer and care recipient, with no other people resident.

Three of the participants were currently working outside of the home on a part-time basis while also caring for the person with Parkinson's disease. Thirteen participants had been working outside of the home prior to undertaking the caring role. Of that figure, seven individuals had planned retirement and this was not related to the caring role. Four participants stated that they had not worked outside of the home either currently or prior to their caring role.

There was a wide variation among participants on the longevity of the caring role, with length of time ranging from one year to 20 years, with the mean length of time caring at 6.15 years. Fifteen of the twenty participants were providing physical care as part of their role.

Table 2.1 Socio-demographic profile of study participants

		Number of Family Carers
Gender	Male	6
	Female	14
Age	<25	0
	25-34	0
	35-44	0
	45-54	1
	55-64	6
	65+	13
Marital status	Married	18
	Widowed	0
	Divorced/ separated	2
	Cohabiting	0
	Single	0
Location	Urban	11
	Rural	9
Relationship to care recipient	Wife	13
	Husband	6
	Daughter	1
	Son	0
Living with care recipient	Yes	20
	No	0
Household composition	2 persons	19
	3 persons	0
	4 persons	1
	>4 persons	0

2.7 Data analysis

All interview recordings were professionally transcribed. All transcripts were then collated and themes/codes were identified through the process of thematic analysis. Care Alliance Ireland took the decision not to purchase specialist computer software to assist with the management of analysis, as it was felt that its added value would be minimal. Instead, the researcher took the following intensive steps in coding the data around themes:

1. Transcripts were read through on a number of occasions, while recordings were also listened to. Recurrent topics were identified; they became the codes and themes.
2. Codes were then categorised under headings depending on their relevancy and the focus of the research project.
3. The connection between codes was investigated. These codes were then re-examined in light of the goal of the research project which was to explore how Family Carers experience and perceive their own health status.

It is important to note that informant feedback or 'member checking' was not used following the completion of interviews. This could therefore be viewed as a potential limitation of this research project in terms of the credibility and validity of the study findings. However, provisions were taken to ensure that informant feedback following the completion of interviews was possible where the researcher saw necessary. For instance, all participants were aware that they may be contacted by the researcher following the completion of the interview in order to clarify any points made if necessary in a follow-up interview. Participants were also given the opportunity to receive a copy of the transcript of their interview. Both points were clearly stated on the consent form. At the same time, informant feedback did take place during the actual interview process. Throughout the interview process, the researcher was keen to restate information or question the participant on comments they had made in order to ensure accuracy and the correct interpretation of data.

2.8 Ethical issues

Care Alliance Ireland and the Parkinson's Association of Ireland believe that quality research and ethical research go hand in hand; therefore, adhering to standards of ethical good practice at all times during the course of research project was essential. Before research commenced, approval was sought to the Board of Directors of Care Alliance Ireland.

Permission was sought by the Chairperson of the Parkinson's Association of Ireland to use the database for the purposes of this research, under controlled conditions. Following discussions, the Parkinson's Association of Ireland was very happy to assist in an area of Parkinson's research that has considerable gaps. The researcher also followed the Ethical Guidelines set out by the Social Research Association (UK) throughout the design, execution and reporting of the research project.

The principles of informed consent as well as participant well-being were given priority over the research objectives at all times. It was acknowledged that some Family Carers may have found recalling their personal experiences saddening. It was therefore agreed to stop or suspend interviews if the participant became distressed in any way. While no participant felt the need to do so, several did reschedule the interviews due to caring commitments. Careful thought was also given to the following ethical issues during the course of the research project:

- All information gathered was kept anonymous and confidential
- Participants' right to privacy was upheld at all times
- Each participant was allocated a code known only to the researcher
- All data stored on the computer was password protected and all research materials were secured in a locked filing cabinet

2.9 Limitations

We acknowledge that the findings of this qualitative research project represent the views expressed by a specific group of Family Carers providing care to a person with Parkinson's disease. Due to the methodology chosen, it is therefore difficult to generalise the findings among the wider Family Carer population. However, given that this study is in part a follow-up to a previous quantitative survey (Care Alliance Ireland, 2008) and the similarities noted in the findings of this study with the former, as well as with other research on Family Carers, we believe that this goes some way to validate this work.

2.10 Conclusion

This chapter has summarised the organising principles that were considered in order to undertake this research project. A qualitative methodology was chosen, involving a series of semi-structured qualitative interviews. Transcripts underwent extensive manual scrutiny through the process of thematic analysis.

Chapter 3: Findings

3.1 Introduction

In this chapter of the report, the main findings of the research will be outlined. Following extensive data analysis, four main themes emerged. The table below gives an overview of the main themes and related sub-themes:

Table 3.1 Main themes and sub-themes of the research

Main themes and sub-themes
1. The experience of the Family Carer <ul style="list-style-type: none">➤ role of Family Carer➤ feelings towards caring➤ coping techniques➤ relationship with care recipient➤ contribution to overall care
2. The impact of caring <ul style="list-style-type: none">➤ Life before caring➤ The physical impact➤ The emotional impact➤ The social impact➤ The positive impact
3. Support <ul style="list-style-type: none">➤ Formal support➤ Informal support➤ Financial support
4. Needs and interventions <ul style="list-style-type: none">➤ Future➤ Time to self➤ Support from family➤ Formal support➤ Exercise➤ Training

3.2 The experience of the Family Carer

All participants outlined what caring for a person with Parkinson's disease entailed. This theme is broken down into four sub-themes, namely: the role of the Family Carer, feelings towards caring, coping techniques, relationship with care recipient, and contribution to overall care. Each sub-theme will now be presented and discussed in turn.

Role of family carer

Participants spoke at length about the tasks they undertook as a Family Carer to a person with Parkinson's disease. The intensity of care required depended on the severity of the condition.

Several Family Carers were undertaking what might be describes as 'medium level' caring; assisting with the main responsibility of household chores:

Basically I would see my role as giving caring assistance to X through being there for X, looking after his meds, taking him to appointments, undertaking the household chores like cooking, shopping (P12).

Other Family Carers expressed their role as involving mainly companionship. While physical caring assistance was not necessary in the main, the emotional support they provided was vital:

Mental support...that's the big thing.

The presence of the Family Carer was the important aspect:

I would sum it up by saying 'being there' (P05).

'Newer' Family Carers of people who were recently diagnosed with Parkinson's disease and still able to maintain certain levels of independence, did however recognise what lay ahead:

It's not going to get better, only worse (P05).

Providing care to a person with Parkinson's disease was viewed as a long term role and the deterioration in the condition was understood to be a gradual process by those who had provided care over longer periods:

It's going on a long time. And I suppose that wears one down...in terms of years...it's been a long tough road (P06). It just grew gradually over a long period of time (P17).

For many Family Carers who had been providing care over longer periods of time, significant changes in the role they provided and the associated responsibilities were noted as the person's condition deteriorated:

It has changed in that it's more hands on (P06).

For some, this process was gradual and they felt able to deal with it:

Well it's so gradual that you probably don't even notice it until you look back over it and see what you do (P15).

The role of Family Carer led to a situation where traditional roles and expectations within the family changed, with several Family Carers undertaking duties in the household they would have not done beforehand, as evidenced by one male Family Carer:

I never washed clothes in my life and didn't know how to put the washer on. I never cooked in life. I now have to cook. I have to know how to put on the washer (P17).

Many participants recounted having high levels of physical demands placed on them in their caring role:

If X wants to get up, you have to lift her up and help her to get up, if she wants to go to the toilet, you have to help her do that (P03).

With this increased physical responsibility, there was an associated responsibility of undertaking personal assistance:

X now needs a lot of help getting dressed as he wouldn't be able to manage (P18).

The level of physical assistance required could vary depending on how the person was feeling and responding to certain medications on any given day. Many of the people with Parkinson's disease were also experiencing bladder problems. Participants spoke about the physical responsibility associated with this, often at night time, such as the changing of bed clothes:

Sometimes if X slept heavy and he can't get himself mobile... he just can't make it down to the bathroom... so there'd be a flood on the bed, then you'd just have to deal with it (P08).

Some participants expressed that their role and presence was constant:

I'm tied to the house 24/7 (P03).

He needs someone night and day now (P09).

Many of the Family Carers who had the heaviest constant physical responsibility associated with their role also expressed feelings of strong emotional strain and pressure, as the person became totally dependent on them with respect to activities of daily living (ADLs):

I am like a slave, do this, do that, get this (P01).

Feelings towards caring

The opinions and emotional reactions revealed by the participants towards providing care to a person with Parkinson's disease varied. Many Family Carers felt that it was expected that they would provide care and saw it as part of their duty and the relationship that they held with a specific family member. They would also expect the same, if the roles were reversed:

Well I've made that promise in sickness or in health and so that's the deal. We've had a good life and that's a part of it (P14).

I feel I have to do it, not that I have to do it, I just feel the need to do it because he needs it and it's up to me to look after him... I mean you don't love someone for 38 years and then just dump them (P18).

However, some participants found this sense of 'obligation' difficult to deal with:

I feel it's an obligation on me... that's kind of been dealt me... it's difficult (P06).

Certain aspects of providing care were difficult for Family Carers at first, such as assisting with personal care:

I'd have to help X to sit down on it (toilet) and get up off it... I'm kind of getting used to it now. I've come to accept all these things. It was hard at the start but... (P17).

At the same time, some participants expressed feelings of resentment towards their role and the expectation of undertaking it:

I feel sometimes like everyone's having a bit of you and where's the bit for me (P08). So that's where it's hard that everything depends on me, that's where you're bound to build up resentment (P01).

While some expressed negative feelings about providing care, the alternative was too difficult to imagine:

If it (long-term care) were offered to me tomorrow I don't know how easily I could let X go (P06).

Negative feelings towards caring expressed by participants were related to the aspects of care that Family Carers found challenging. For instance, some specific symptoms of Parkinson's disease such as the changes in the person's personality and behaviour became difficult to deal with:

I suppose the mental aspect of it; you know when you can't get through to X. That can be difficult. I mean when he is asking you the same question and you're giving him an answer and it's not just going in (P18).

Another challenge faced by participants was the deterioration of the cared for person's condition and the related need for the Family Carer to be constantly present. This was both a source of upset and frustration for some. For instance, providing care during the night and the associated broken sleep was demanding:

Well the night time is a bit hard you know. It's hard when you have to get up at 5 o'clock in the morning, to get out of the bed (P09).

Trying to stay positive was important for some:

Well I find it all, every day I get up, a difficult task, but you try and ignore the bad things and the way you feel... take the good with the bad (P03).

Coping techniques

Participants referred to ways in which they handled and dealt with the role of Family Carer to a person with Parkinson's disease. Time to self and the ability to undertake personal interests, if only for very short periods, was seen as vital in order to maintain the ability to provide care:

I suppose to try to relax and switch off. I find it helps; I can do that best when I'm at my art class (P11).

Regular exercise was seen as a beneficial way of relaxing for some participants:

The best chilling out you can have is a walk... it can enter your mind and you feel great when you come back then (P20).

Regular contact with friends was also seen as important:

I have a great circle of friends to socialise with (P07).

Support in the role of Family Carer was essential to all participants in sustaining their ability to continue to provide care. There were various types and aspects of support received; these included respite services, home-based care, healthcare professionals, family and financial. Availability and access to support differed among participants and is outlined under the theme of Support in a later section.

Relationship with care recipient

Significant changes in the relationship with the person who had Parkinson's disease were noted by Family Carers. Negative aspects referred to were the frustrations that participants had with changes to the person's personality and behaviour as a result of the condition. These could be both irritating and annoying at times:

At night time... the fidgeting goes on... he is from the chair to the wheelchair... And that goes on... and that sometimes can be very irritating (P01).

In addition, several of the care recipients had also been diagnosed with a secondary condition:

When the dementia is there he can get very confused and very frustrated, he doesn't know me and he's calling me all sorts of names and he's calling me his sister who's dead (P18).

In cases where the condition of the person had dramatically deteriorated, several participants saw their relationship together as nothing more than 'caring':

It's purely a caring role now. It's nothing... there is no other kind of, as it were, a relationship (P06).

Well I mean X needs so much doing for her, so there isn't much backwards and forwards between us, because you're doing things all the time (P14).

Some participants noted changes in the roles within the relationship between Family Carer and care recipient, as a result of Parkinson's disease:

Well it's changed in that he is very dependent on me now... he is not able to make decisions so I'm as they say: 'Mum has all the money now, do you know what she is doing Dad?' (P08).

I tell you it's a big responsibility. I mean X was always the one that looked after me (P01).

Some participants noted that caring for the person with Parkinson's disease had in fact resulted in positive changes to their relationship:

Well I think it's (caring) brought us closer (P16).

Contribution to overall care

Participants were asked what they felt was their input into the overall care of the person with Parkinson's disease. The majority of participants believed that the person would not be able to cope without them being present and would end up in long term care:

X would be hopeless on his own. I don't know what we would do (P05). Well if I wasn't there I don't think X could stay at home. So all I'd say is that it's cheaper than putting her into a home and X wouldn't want to go into a home (P14).

There was a hope that other family members would look after the person with Parkinson's disease, if participants were unable to provide care. At the same time, they did not want to burden them:

I hope the children would look after him. But then that is an awful lot to ask somebody to do (P08).

3.3 The impact of caring

Caring for a person with Parkinson's disease was seen to have a multi-dimensional effect. The care provided by many participants in this study had a significant impact on many different aspects of their lives. The impact of caring had many layers; physical, emotional, social and positive. Each aspect and the associated impact on the life of the Family Carer will be presented and discussed in turn. In parallel to the impact of caring, another sub-theme emerged – life before caring. This will be outlined first.

Life before caring

Participants spoke about what life was like for them prior to undertaking the Family Carer role. Many participants referred to how they had been able to pursue interests they had when they wished, with no need to plan ahead:

Just being able to do things for myself on the spur of the moment, without planning ahead (P12).

There was a sense of loss for the 'life before caring' for many participants:

You miss doing things for yourself, naturally, big time (P03).

A loss of the companionship previously held with the person who had Parkinson's disease was felt by some:

We used to just, we were just a very together couple (P18).

Other participants believed that there was no comparison between what life was like now versus life before:

Not a comparison, it's a whole new life (P10).

The physical impact of caring

Providing care to a person with Parkinson's disease had a series of real and tangible effects on the lives of many participants in this study. In general, the intensity of the physical burden experienced depended on the severity of the condition and the level of physical care provided.

The physical responsibility to family members with Parkinson's disease required many Family Carers to undertake substantial physically demanding roles:

From the minute I wake up in the morning and go to bed (X needs me) (P01).

Well it's very challenging. You can't relax. I mean...it's physical things X needs (P14).

One aspect of caring for a family member with Parkinson's that many found physically demanding was night time care and the impact this had on the participant's own sleep:

When it's time to get up I'm exhausted. I've been asleep about an hour, you know, how do you go back to sleep, but I get up and that's it (P20).

The need for a constant presence was mentioned by many participants, particularly as the person's condition deteriorated:

You couldn't even go outside the door and you'd have to go back in again (P03).

Many Family Carers did not want to leave the person with Parkinson's on their own:

But as the years go by, it would affect me, I wouldn't go away and leave her on her own (P15).

I've been sort of isolated, and you're tied, you know... X needs someone night and day now (P09).

The physical demands of the Family Carer role led to a situation whereby many participants had to make significant adjustments to their daily routines:

You don't be able to do as much in the mornings (P02).

So going to the shops... because you don't know how long you are going to be delayed or whatever... I will take X. But then I might have to leave X sitting in the car (P06).

Planning ahead also became difficult, due the high levels of variability in the condition:

You can't plan each day, the odd time you can but you have to take each day as it comes and see if X is having a good day (P18).

Some participants were combining providing care with working outside of the home. While other participants had previously worked outside of the home, they felt that they were no longer able to combine this with providing care, as the physical demands of the role intensified:

Now if his health hadn't broken down I would have been (working) until I was 60 (P07).

I gave up work and took early retirement to be here for X as I couldn't stand the thought of him being left alone (P12).

The physical aspects of health and well-being associated with the constant physical presence and high level of manual assistance required in providing care to a person with Parkinson's disease were discussed by participants during the interviews. Many were experiencing high blood pressure:

It's anxiety and my blood pressure has gone up very high... it passes on to me (P01).

Participants also referred to having difficulties sleeping:

I don't sleep very well. I am anxious about X (P01).

Tiredness was another issue:

I think I'm only tired now, it's a different kind of tiredness... it knocks me sideways. You don't realise that, but know I think when I look back I think the only tiredness I have now is just being trapped and going constantly because you don't get a break (P03).

A lack of physical energy was also mentioned:

I mean it takes a bit longer to do things. It definitely does, and I don't have the energy I used to have (P20).

Some participants used medication to help them sleep:

I have a sleeping tablet at night and if I don't I have nightmares (P03).

Back problems were noted:

Lifting X in and out of the bed at night. I have a bit of a bad back (P18).

I mean getting that wheelchair, I've actually got pains in my back, getting that wheelchair in and out of the car is quite something (P07).

Some Family Carers were experiencing arthritis and as a result particular aspects of providing care proved difficult:

I've got the arthritis... it's the back of my neck. I do everything with the minimum of me actually lifting X (P08).

My arthritis tends to play up at times after doing the housework... Also I find it hard during the days when I've been up with X during the night (P11).

While some participants did seek medical advice and necessary treatment for their own physical ill health, others did not, citing a lack of time to do so:

I've already got high blood pressure... And that's something that's been going on and off but it's getting higher and I'm supposed to put the monitor on, but I haven't had a minute in the past fortnight to phone and say to the nurse can I come in and get my monitor (P08).

Several participants recalled having experienced life-threatening physical health conditions themselves, such as cancer and bronchitis, prior to undertaking the caring role.

At first glance, many participants felt that their own health was satisfactory. However, upon close analysis of data, it would seem that Family Carers were in fact overlooking their own health. For instance, when asked 'How is your own health?' many replied with comments such as '*I'm fine*', '*Not too bad*'. However, during the course of the interviews, the same participants expressed that caring for a person with Parkinson's disease was having a negative impact on their physical and emotional health and well-being. There was a worry associated with what may happen to the person with Parkinson's disease should they too become unwell and unable to continue to provide care:

If I was sick tomorrow, I don't know how X would cope or I would cope (P01).

Indeed, worrying over what may happen was itself a source of emotional ill-health and is discussed in the section below. Some participants believed that ill-health was part of getting older and not related to the caring role:

When you get older you start getting a few ailments (P19).

The emotional impact of caring

The constant physical presence and high level of manual assistance required in the role of Family Carer had a powerful effect on the emotions and feelings of many participants.

For instance, the gradual deterioration of the person's condition was difficult for some to deal with; particularly where changes in personality and behaviour were noted:

He can be very aggressive with me and I find that very hard (P01).

Some participants expressed feeling emotionally strained in the role:

(My doctor said) I was stretched...mentally I think...I need to keep my health well (P20).

In some cases, the person was also diagnosed with a secondary condition:

For the most part it doesn't overwhelm me in that sense... except for in the last... he is suffering more brain impairment and he has an element of dementia now (P06).

Feelings of frustration and unhappiness in the role of Family Carer were noted:

Some days I can get very agitated... some days I get like ahhh (P13). There are times when... I will be crying... the physical non-ending of it (P06).

Loneliness as a result of providing care was expressed:

It's only when I walk into the house on my own, Oh God, and I realise the loneliness of this work (P03).

The demands of the caring role, and the associated inability to interact socially to the same extent as previously, resulted in feelings of isolation:

What freedom have I? (P03).

The restrictive nature of caring was an issue:

I find the days I don't get out are the worst (P12).

Periods of depression where participants expressed feeling sadness and negative thoughts in the role of Family Carer were noted by several participants:

Sometimes you get low and get irritable (P12).

Thinking about what may have been was upsetting:

I get depressed... I have a feeling I would love a good cry. Because if X was well... we would be doing so much (P01).

The almost 24/7 nature of some caring experiences was also a source of depression:

I have a problem with depression... the night time is a bit hard you know. It's hard when you have to get up at 5 o'clock (P09).

The almost invisible nature to others of how Family Carers were feeling and the necessity for them to remain 'healthy' in order to carry on in their role was noted:

Although I may look okay, inside I feel terrible. I'm finding this whole thing difficult to cope with and I get very down about it... I was avoiding it but eventually went to my GP, he's put me on anti-depressant tablets. The thing that gets me is that everyone expects you to be fine, you have to be, you need to be (P12).

It was also remarked that the onset of periods of depression did not follow a certain course and could indeed happen at any time:

And you see with depression, it can come out of the blue, and it won't go either cause I had to be in hospital several times. That's a horrible feeling (P10).

A feeling of worry was commonly expressed. Many participants recalled feelings of nervousness and anxiety as a result of providing care to a person with Parkinson's disease. For instance, many found that the person was always on their mind and therefore became a constant source of worry:

I am nervous of X in the shower by himself due to his tremors (P11).

This had a physical impact, such as difficulty sleeping, for some:

I don't sleep very well. I am anxious about X all the time. You know, it rubs off you (P01). You get a lump in your stomach. When you go to bed you have this lump in your stomach... (P03).

Other Family Carers noted that as a result of constantly worrying, they were unable to relax:

Some days I'd love to go out on my own, go into town, then when I'd go in, I'd be thinking about getting back, thinking about X (P13).

A major source of worry for many participants was the apprehension caused by thinking about what would happen to the person with Parkinson's disease should they be unable to provide care, for example if the Family Carer became unwell:

I worry that I'm going to die before X, because of the age I am (P08). And if anything happened to me, you know, what would happen to X? (P20).

Some Family Carers felt that worrying was itself a cause of ill-health:

I try not to, when I think about what might happen to X, my blood pressure goes up (P11).

The uncertainty of what lay in the future was also a source of concern, particularly as the condition of the person with Parkinson's disease continued to deteriorate:

Well I suppose you always worry as it gets worse... and then there'd be toilet problems and all sorts of things, you know, down the line (P15).

The possibility of the person having to go into long term care in the future caused feelings of anxiety:

I worry about X because I don't know what's going to happen to X you know and it would break my heart to see X going into residential care (P09).

Some Family Carers tried not to worry, so as not to impact negatively on their own health and well-being:

I never worry about anything... I won't let myself... It won't do me any good (P07).

There was, however, agreement that the person's condition was not going to get better, only gradually worse over time:

I think I know what's going to happen to X, so it's just a question of how far down the line that's going to happen (P18).

The social impact of caring

Providing care to a person with Parkinson's disease had a strong social impact for participants in this study. As previously mentioned above, many expressed feelings of loneliness as caring for someone with Parkinson's disease resulted in a restriction of time to self and the ability to participate and interact in social activities or interests, particularly as the condition deteriorated:

I've no life now because I was safe to go wherever I wanted to go, knowing X would be fine but then... like I'm stuck to him all the time (P10).

Certainly your freedoms go in the sense that you took for granted as you know being able to do... going off for a few days... they're all gone, those days are all gone (P20).

Well it just means that I don't do loads of things that I used to do now. I don't say I miss them. I miss the ability to do them more than I actually miss them (P14).

Other participants found that they had to make significant adjustments to their social life as a result of providing care:

Weddings or anything, they all have to be kind of managed. There's no such thing as go along with the crowd, or if you went to something you'd have to make sure that... you have to get a chair, X would have to be sitting down (P15).

Friends played an important role, particularly as a way of maintaining social contact and 'switching off' from caring, when given the opportunity to do so:

My friends are my hobbies really... I think it's important to have your own friends. I definitely do (P20).

Speaking with friends was also a way of sharing feelings about providing care. However, there was also a fear of over burdening friends with their own problems as a Family Carer:

With your friends, you don't always want to be the moany one either you know... however good friends they are, you have got to be upbeat, you can't keep moaning about... people will only listen for so long (P05).

In some cases, friends also provided a vital source of support:

A friend of ours drives up (to X's medical appointments) (P04).

The positive impact of caring

Whilst acknowledging the overwhelming negative aspects associated with providing care at present, several participants referred to the beneficial elements that providing care had on their own life, particularly with regards to thinking about what would happen in the future:

What I gain you couldn't... like I've gained so much now... I know some day I'll be able to walk out that door and do my own thing (P03).

Other participants felt that through providing care, they had in fact become closer to the person with Parkinson's disease:

Since Parkinson's we're probably doing more things together... Yeah, it's nice (P02). I do feel we have become closer, whether it's because we're together nearly all day, but I usen't feel the same way (P11).

3.4 Support

The provision and levels of active assistance available in their role as Family Carer were discussed at length by participants. This theme is broken down into three sub-themes; formal support, informal support and financial support. Each sub-theme will be outlined in the following sections:

Formal support

Participants recalled their experiences of respite and day care services as a Family Carer of a person with Parkinson's disease. Many of those who were providing care to a person with higher level demands were receiving periods of formal respite. Respite was viewed as essential in order to give participants a temporary break from the role of Family Carer, in order to allow them to have time to themselves and participate in society. While the quality of services provided was not questioned, many felt restricted in what they could do as the current timeframe given to them was insufficient. There was an urgent need for longer periods of respite:

But it's just... you are... you know you can't go very far. You have to be back, I have to be here when X comes back (P06).

Instead of a period of temporary rest from the role, some participants undertook tasks that they were unable to do while providing care, for example, grocery shopping:

The whole idea is to give me a couple of hours... to get some time to myself, that I can go and do a shop without... I am watching the clock (P01).

In some cases, the wishes of the person with Parkinson's resulted in little or no respite for the Family Carer:

X wouldn't go into respite... one day I went down to see the respite which is lovely... but there was no guarantee that he would have a private room. I wouldn't be happy. If he's unhappy, I'm miserable. He'd be just unhappy, I'd be miserable because I'd take it on (P07).

I mean I've only had respite care now for two periods (for a number of days). One was last year and that was a disaster... well X wasn't happy in the respite care place (P14).

Several participants expressed feelings of guilt at taking time out from providing care through respite services:

Sometimes if you are doing these things, you kind of feel guilty that you're letting him down and you're pushing him away, you know (P18).

Experiences of home help services received through paid carers providing home-based support were discussed by participants. The presence of home-based support allowed participants to undertake activities outside of the family caring role:

The only time you go out is if (paid carer) is in (P08).

It was overwhelmingly felt by those who received home help services that the current amount of time allocated through state-funded support was insufficient:

Eight hours a week, I mean it... that is nothing (P01).

Several participants noted that the home help support had recently been cut back:

I must say that they were very nice. But that it's only four hours a week now, it used to be ten. It was cut back... it's not a lot, when you have been all day... (P10).

In some cases, paid carers assisted with the physical, manual aspects associated with caring such as washing and dressing of the patient; while in other cases, paid carers undertook general household chores.

Trust in the paid carers' ability to provide an adequate source of care was vital:

I feel very comfortable with the carer because I know that no matter what happens X can deal with because she's been doing this for 20 years (P08).

Several participants did not like the idea of home-based support through paid carers:

I don't see that as great because to benefit from that I would have to get out... And then to find that I have to be out every day or every afternoon... that wouldn't particularly suit me... And yet having somebody here we would be getting in each others' way... you couldn't cut yourself off from what was going on (P06).

Some participants were currently not receiving home-based support but it was something they thought about, particularly as the person's condition deteriorated in the future:

Well I would say if her condition deteriorated we would probably need a full time daily help (P04).

The insufficiency of the state-funded home-based support services provided through the HSE led some participants to pay carers from the private sector to assist with care in the home:

Well my overall experience as with the HSE, it has been a disaster, I mean I was worse off having them than not having them... I mean it could have been just 'that's the way it is and got to put up with it' (P14).

I applied for the grant and we got a grant for the three days and the other two days I kind of paid for the extra hours myself (P18).

State-funded support at night time was identified as particularly problematic:

It's very difficult, unless you go out and pay for your own help to come in at night (P03).

Participants recalled varied experiences of the support received in their role of Family Carer from healthcare professionals. Some welcomed the support received from the Public Health Nurse:

It's important that there's somebody like the District Health Nurse that you can ring and leave a message or drop a note down to her and she will follow it through. You need someone batting for you. She is the one that bats for me, looks out for me as much as she looks out for X (P07).

However, many were highly critical of the role played by the Public Health Nurse, with many receiving little or no support:

I feel let down ...like the public health nurse didn't even call and I rang her last week looking for equipment and she has lost his file (P09).

While many participants had a good relationship with their GP, some were frustrated by the lack of support they received:

It was like talking to that (knocks on the table)... don't get me wrong, doctors are good but sometimes you have to shout at them (P03).

Assistance received by other healthcare professionals such as Occupational Therapists was also commented on:

The Occupational Therapist... they make it (my life) a little bit easier (P13).

Difficulties in the provision of and access to information on entitlements to support for Family Carers were also a major issue:

If you have a problem you must go and look for help. Nobody's going to go and come looking for you (P16).

I didn't even realise the entitlements and services that were available to carers until my daughter told me (P12).

Some participants preferred not to receive formal support:

Well I suppose I'd be slow to look for support... I suppose it's my make up... I'd be fairly independent... we'd be fairly private in our ways (P15).

For 'newer' carers they felt that they were still learning about what was available to support them in their role:

We are sort of muddling through at the moment (P05).

Other participants believed that nothing further could be done, as the person's condition deteriorated:

I can't see what anyone can do, I mean, what can someone else do? (P17).

Informal support

Participants spoke of varying levels of informal assistance in the role of Family Carer from other family members. Support received from other family members was often vital for Carers in order to have some time for themselves and to participate in social activities:

She (daughter) was out at the weekend and she gave me a couple of nights out and she stayed (P17).

The physical presence of family members was also important:

He'd (son) often stay a night to make sure everything was alright... He would be available for anything (P20).

In some cases, family members assisted through making necessary adjustments in the home:

Our son put in special rails in the bathroom so X can hold on to them (P11).

Support from family members was crucial when Family Carers themselves became unwell:

Well the only thing that saved us was my daughter, who flew over from England and looked after us for the week till I got better (P14).

Several participants experienced an absence of support from family members:

It makes me feel terrible because I'd like to go to a wedding now and then. I'm under pressure to go and I'm under pressure to stay and I don't know... there's no one to stand in (P09).

Feelings of isolation were noted where relations with family members were virtually non-existent:

And it does hurt me... I was frightened in the beginning and I thought... they didn't want to know... I thought they distanced themselves (P06).

Frustrations and tensions with family members were recalled by some, due to a lack of understanding of the Family Carers' own needs, where family members did not offer assistance:

I need the switch-off time. And that's where I don't think they understand that I need to switch off from this. They see me as Mum doing cooking, Mum doing this, Mum doing that... you're not looking for sympathy but they don't realise that I get as tired as I do... it's nice to have their company but it would be equally as nice if they came along and when you're stuck like, did something (P08).

Issues relating to looking for and agreeing to support from family members were raised by some, such as not wishing to overload obligations that they may already have:

They are busy with their families, they are working and they have families, so they don't really have the time to come so that's where it's hard (P01).

One participant noted that they would prefer not to involve family members in the provision of care to the person with Parkinson's disease:

I think I'd nearly prefer someone outside coming in (P10).

Assistance received through the NGO sector was also discussed by participants. Many spoke very positively about the support received through various NGOs with regards to the provision of information both on what being a Family Carer entails and education on the condition of Parkinson's disease itself:

They're very informative to us... keeps you up to speed with what kind of drugs are available... because otherwise I probably would have been in the dark for all this (P02). You do learn little things... told you things you didn't know sort of, and to be prepared for things (P13).

Attending support meetings had a social aspect to it as well as gaining information, as it was seen as a way of becoming acquainted with other Family Carers:

I went to that mostly just to go and meet other people and used to have a little laugh... I went along for the cup of tea and then you'd be surprised at that conversations come up and what things you might be entitled to... all sorts of different conversations so yeah, I found that helpful (P08).

However, several gaps in current service provision were noted. The distance to travel to support meetings was seen as problematic for some:

The only thing would be if there was somewhere nearer... it's like a day out (P02).

The presence of the person with Parkinson's disease at some support meetings made some participants feel uncomfortable:

I would like to be able to talk or interact more with carers. Because when we go to X meetings, they are very good but you can't say too much... well you can't in front of X... he will say 'what are you asking that for?'(P05).

Many believed that a support group exclusively for Family Carers would be beneficial:

I think it would be a good idea if they did something specifically for Family Carers, without people who have Parkinson's disease (P11).

Yet issues were also raised concerning difficulties attending a support group alone and the need to have someone present to care for the person:

How can you? They had a lovely outing... I would have loved to have gone but it was the very time I couldn't get anybody (P03)

I think about what if I do join? X can't really be here on his own (P18).

Financial support

The level of state support received through financial assistance in the role of Family Carer was criticised:

I have the carers' allowance... well if I was depending on that alone, no way, no way. How could it (be sufficient)? (P03).

It was strongly believed that Family Carers deserved recognition from the state for the contribution they were making:

Yet they (the state) don't accept that I provide one-to-one care round the clock... without acknowledging it (P06).

It's cheaper for the Government to have selected me, an unpaid carer, I feel I'm entitled to money... everybody who is doing it should have some sort of tax allowance (P07).

The need to save for the future was raised, as the person's condition worsened, particularly in the absence of adequate state support:

I would say I have built up a bit for the future... if the state doesn't help me, I'll try and help myself (P15).

3.5 Needs and interventions

Participants were asked about their own needs and any possible actions that could be taken in order to contribute to their health status in the role of Family Carer.

Some participants mentioned that they did not think about their own needs:

I never really thought about it (P18).

I don't want all that much (P10).

Other participants believed that they were managing in their role at present but could envisage a time in the future where interventions might be necessary as the person's condition continued to decline:

At the moment really I suppose we're coping okay... but if you talk to me in a year's time it could be different (P15).

Firstly, time to self and the ability to take a short break from the role of Family Carer were seen as essential to participants in order to maintain the strength to carry on providing care:

What do I need? Just time out I suppose (P05).

It was viewed as an important way of relaxing and 'switching off' from the role:

I need the switch-off time (P08).

You just need to have breathing space (P18).

Time to self was also a key means by which participants could pursue personal interests:

I'd like to do some classes at night... I'd like to do computers (P09).

For many, time to self was a rare occurrence and for very short periods. In order to have a significant impact, it was seen as essential by several that Family Carers receive extended periods of time to self:

That's what you need. You need to get a break, and you want a day, you want a full day, not just two hours. And you need a night off; you need a holiday (P03).

Support from family members was seen as important in order to enable the Family Carer to have time to self and in so doing have a positive impact on their health and well-being:

That's the only time when you can go out with a free mind, is when you know that you've got a family member there and they can stay, you haven't got a time to be back (P08).

However, when this support was absent, it could have the opposite effect, creating feelings of loneliness in the role of Family Carer:

Well I suppose it would help if some of the family could cover on the care or help out but they don't (P09).

Respite and day care services were viewed as a fundamental way in which participants could gain a brief time-out from the role, thus maintaining their own health and well-being.

Well I certainly appreciate (it). It does give me a chance to... clear my head a bit... sit down... maybe read the paper or whatever... without X to go out and do something... go to the shops or whatever it is...without (P06).

When you have respite care you can go away and that's it sorted, you know you can go away and you don't have to think (P14).

Attendance at a day care facility was seen as also being beneficial to the person with Parkinson's disease:

The thing I would like would be a day centre that X could go to, so that one day a week she was meeting other people (P14).

Assistance in the role through the provision of home-based support was mentioned by participants as another important intervention required to maintain their health and well-being and meet their need for time to self:

So that you'd feel like you weren't stuck in the house (P10).

Upon receiving support through a paid care worker, one participant recalled:

I think I'm very healthy for my age. The only thing is I don't walk enough but now that (paid carer) is here I can walk to work and walk back because before I was kind of just leaving at the last minute for work, driving and I was rushing back home again, driving, so I know now I can walk up and walk back and take my time (P18).

Regular exercise was seen as a crucial way in which some participants maintained their own health status:

Well they (exercise classes) are definitely beneficial (P20).

My GP says... I have to walk; I've got to walk at my own pace for my osteoporosis as well as my general well-being (P19).

Getting an appropriate amount of sleep was also important:

I decided I was going to try and get to bed by 10 pm (P08).

A support group exclusively for Family Carers was seen as having numerous benefits, such as sharing and gaining information on rights and entitlements and a way in which new friendships could arise. Issues were raised among participants concerning attendance of joint support groups for both the Family Carer and person with Parkinson's disease. Support groups specifically for Family Carers are also discussed further under the theme of support.

The majority of participants had no formal training in the provision of care. Many believed that a programme of training would have a positive impact on their own situation, and thus be of benefit to their health status:

You could be doing it the wrong way and it would be good to learn as much as you can (P03).

Training was seen as important, particularly as the condition of the person deteriorated and the caring required became more physically demanding:

It's something that could be useful particularly as X's condition changes (P11).

While the importance of training for Family Carers in the physical aspects associated with providing care were seen as crucial, training in relation to dealing with the emotional aspects linked with caring was also vital:

Training as regards say de-stressing and maybe mentally too... training your attitude towards... the person you are caring for... like how to feel emotionally... if it's like... when you have got somebody who is... say anxious and depressed, how to deal with them... training me how to deal with it... I get frustrated at times (P05).

3.6 Conclusion

This chapter has presented and discussed the four themes which emerged in this qualitative piece of research. It is clear that no one theme stands alone, instead each is intricately interconnected and together represents an exploration of the overall health and well-being experience of a specific group of Family Carers, namely those who provide care to a person with Parkinson's disease. The main findings are considered further in the following chapter.

Chapter 4: Discussion and Conclusions

4.1 Introduction

In this final chapter of the report, the main findings will be brought together to be discussed and summarised. A number of key recommendations will then be made in relation to Family Carer policy issues. Possible avenues for the focus of future research will finally be outlined.

4.2 Discussion of key findings

This research project develops a greater understanding of the current health status of Family Carers in Ireland, thus continuing the initial work undertaken in the 2008 Care Alliance Ireland Survey. In doing so, the findings paint a picture of the 'story of caring' and the experiences of a specific group of Family Carers. The following sections will consider the main themes of this study which transpired following detailed analysis, with reference to other work in this area undertaken to date:

The experience of the Family Carer

The physical demands and associated physical responsibilities, as well as the emotional aspects of the caring role, were identified and reflected the severity of the condition. The physical aspects of the role intensified as the person's condition gradually worsened over time and the level of assistance required could vary dramatically on a day to day basis. Hirst (2005) demonstrated that moving into a demanding care-giving role resulted in increase depression and psychological distress, impaired self-care and poorer self-reported health among carers. Caring for a person with Parkinson's disease was viewed as a long-term role by the participants in this study. In a study by the Parkinson's Disease Society in the UK (2008), 45% of Family Carers of a person with Parkinson's disease were providing care for 10 years, while 10% were providing care for 20 years.

Feelings towards caring differed. There was a sense of expectation associated with providing care that related to pre-existing family relationships and roles. However, this sense of 'duty' was not easy for some, leading to feelings of resentment. At the same time, the option of residential care at this time was not considered. Similar experiences of role change and role conflict were felt by carers in a study by Faria (1998).

Specific aspects of caring for a person with Parkinson's disease were seen as challenging. Assisting with personal care, changes to individual personality and behaviour, the gradual decline in the person's condition, the associated need for an almost constant physical presence and providing night time care were both upsetting and frustrating at times. Indeed, Williamson et al (2008) found that there was a sense of uncertainty and search for understanding in the changing identity of the loved one as a person with Parkinson's disease among Family Carers in their study.

A range of coping techniques in the role of Family Carer were identified such as time to self, the ability to undertake personal interests, taking exercise, contact with friends and the presence of support. Similar mechanisms were recognised by the Family Carers in the Care Alliance Ireland (2008) study.

Caring for a person with Parkinson's disease led to major changes in the relationships that had existed between Family Carer and care recipient, for many in this study. In several instances, the person with Parkinson's had also been diagnosed with a secondary condition such as dementia. Where the person's condition entailed extremely high physical assistance, the relationship, while loving, consisted primarily of providing physical care, with limited reciprocity. Similarly, in a study of spousal carers of people with MS, Cheung and Hocking (2004) found that the care recipient became a different person as result of the progression of the illness, with the care recipient seeming to no longer understand.

The impact of caring

In general, life before caring entailed time to self in order to pursue personal interests, with no need to plan in advance. There was a sense of loss for what life had previously been like, prior to undertaking the role of Family Carer. The impact of providing care to a person with Parkinson's disease was found to be multi-dimensional. In stark contrast to life before caring, for many participants nearly all aspects of the Family Carer's life were affected. Providing care had powerful physical, emotional, social and positive impacts, depending on the severity of the individual condition.

For many, the roles and responsibilities of providing care were both physically demanding and challenging, in particular the night time aspect. As the condition deteriorated, there was a gradual need to be constantly there. A considerable number of Family Carers noted significant changes to their daily routines. Some carers were no longer in a position to combine working outside of the home while providing care, However, several continued in this dual role. The Listening to Carers Report (2008) notes that the lack of sufficient community and home care services often presents an insurmountable barrier to paid employment for Family Carers.

High blood pressure, tiredness, lack of physical energy, back problems and arthritis were all physical health conditions attributed to the constant physical presence and high level of manual assistance required in providing care among participants in this study. This has also been found to be the case for Family Carers in previous studies such as that of Care Alliance Ireland (2008) and O'Connell (2003). Lack of time to access necessary medical treatment for themselves was another issue brought up by several Family Carers in this study. Some carers had themselves encountered life-threatening physical health conditions prior to undertaking the caring role. Worry relating to what would happen to the person with Parkinson's disease in the event that the Family Carer became unwell was also expressed. Indeed, concern over carers' own health and the ability to continue to provide care was expressed by carers in Cheung and Hocking's (2004) study.

Providing care to a person with Parkinson's disease had a strong impact on the emotional health of many in this study. Feelings of frustration, unhappiness, loneliness and anxiety, as well as periods of depression, were all expressed as a result of the physical demands of the caring role. There was a sense of expectation for the Family Carer to be 'healthy', leading them to conceal their true feelings and/or health status from others. Similar impacts on emotional health have been identified in previous work undertaken by Care Alliance Ireland (2008); Cummins (2007); Carers UK (2006); and Boden (2002). The uncertainty of being able to continue to provide care in the home in the future as the condition continued to deteriorate was also worrying for Family Carers in this study.

There was a significant social impact associated with providing care to a person with Parkinson's disease. Time to self and the ability to undertake personal hobbies or interests were considerably limited and/or adjusted in many instances, leading to feelings of loneliness. Both the Care Alliance Ireland (2008) study and O'Connell (2003) noted the significant negative impact that providing care had on the ability to participate in social activities. Friendships with significant others were seen as an important way of preserving the now restricted time to self for the Family Carers in this study.

While the focus of much discussion was on the negative impacts associated with providing care, the positive aspects to the Family Carer's own life highlighted cannot be ignored. For instance, several participants believed that they had become closer to the person with Parkinson's disease as a result of providing care and it had had a beneficial influence on their relationship. This finding concurs with the work of Tarlow et al (2004) who found that there were also positive aspects associated with the caring experience.

Support

Multiple sources of support in the role of Family Carer were identified, falling under the sub-themes of formal, informal and financial support. The provision and levels of support received had an impact on the overall Family Caring experience. Access to respite and day care services were necessary in order to give a short break to Family Carers. However, current periods of respite received were seen as inadequate. As a result of the wishes of the person with Parkinson's disease, several Family Carers received little or no respite. A sense of guilt upon receiving respite was also conveyed. Home-based support through paid care workers was another important way by which Family Carers could gain a temporary rest and take part in leisure and recreation or indeed just attend to daily chores such as shopping. At the same time, issues regarding the inadequacy of current periods of home-based support were also highlighted. Indeed, several had sought additional home care support through paid carers in the private sector due to these inadequacies. Major gaps in both respite services and home-based support through paid care workers in Ireland has previously been highlighted in the Listening to Carers Report (2008).

The findings of this study showed diverse experiences in support received from healthcare professionals. Inadequate levels of support from the Public Health Nurse and GP were expressed by some Family Carers, thus leading to a source of tension. In contrast, support received from other healthcare professionals such as Occupational Therapists was welcomed and seen as beneficial. Further exploration of Family Carers' relationship with healthcare professionals is warranted as it was not within the remit of this study. In fact, Hynes et al (2008) found major gaps in the relationship carers had with healthcare professionals. Problems in accessing information on entitlements to supports for Family Carers were also raised in this study. Newer Carers believed that they were still finding their way through the system. However, there was a wish not to seek formal assistance in some instances.

Informal support from family members was highly valued, although levels did vary. Stotlz et al (2006) point out that the meaning of support for Family Carers in their study was understood as 'sensing togetherness'. Feelings of sadness and isolation when other family members were not present were mentioned by Family Carers in this study. A lack of understanding of the needs of the Family Carer by other family members was also an issue. A fear of over-burdening family members led some to find it difficult to ask for assistance.

Support received from various NGOs was viewed as highly beneficial and a crucial way of accessing information, both on generic Family Carer and condition-specific issues. While attendance at support meetings was seen as a way of gaining knowledge, it also had an important social aspect and was a way of meeting other people in similar situations. Similarly, members of support groups in a study by Munn-Giddings and McVicar (2007) reported personal gains of empathy, emotional information, experiential knowledge and practical information, based on a core value of reciprocity through peer support. Nonetheless gaps also highlighted by Family Carers in this study cannot be ignored. For instance, the distance to travel to support meetings and joint support meetings for both Family Carer and care recipient were problematic. While a support group exclusively for Family Carers was viewed as a possible solution, the need to have someone present to care for the person with Parkinson's disease was another source of concern.

Levels of financial assistance available through the state were condemned. The contribution made by Family Carers was seen as deserving of adequate recognition from the state. Due to the major deficiencies in current state support, the continued deterioration of the person's condition led some carers to save for future needs. Similar strong views on levels of carers' payments not sufficiently reflecting the economic value of providing care were also expressed in the Listening to Carers Report (2008).

Needs and interventions

A range of possible interventions were outlined which could be put in place in order to contribute to the overall health status of Family Carers. Time to self was a crucial way of giving Family Carers a break from the role, and in so doing maintaining their own health and well-being. Support from other family members, respite and day care services, and home-based support were all possible ways that this could be achieved. Taking regular exercise was another mechanism used by some in order to have a positive impact on their own health.

A support group exclusively for Family Carers was identified as being beneficial, as well as a way of exchanging information with fellow Family Carers. It also had an important social aspect.

A training programme for Family Carers was singled out as a crucial intervention that would assist participants in their role and, in so doing, have a positive impact on their health status. The role of Family Carer continued to change, and the level of physical assistance required intensified, as the condition of the person with Parkinson's disease gradually worsened. Learning the skills necessary to deal with the emotional aspects associated with providing care was also viewed as extremely important. Family Carers in the Listening to Carers Report (2008) identified similar gaps in current training available to Family Carers across Ireland. For instance, participants noted the need for training and subsequent refresher courses in the practical skills of caring, personal care and self-care aspects, as well as stress management. Carers of individuals with Parkinson's disease in the UK (Parkinson's disease Society, 2005) felt that their need for advice on emotional aspects of caring for Parkinson's disease had been ignored.

Several Family Carers did not think about their own needs or identify what in fact they were, while others believed that the interventions outlined above would prove vital in the future as the care recipient's condition gradually deteriorated. The Carers Outcome Agreement Tool (COAT) developed by researchers working collaboratively in Sweden and the UK (Hanson et, 2006) could be used as model for working with Family Carers in order to adequately address their needs. Following several years of research, COAT views the carer as a 'co-expert'. Carers and practitioners therefore work together to agree the type of goals and outcomes that carers see as important, and the support needed to achieve this.

4.3 Policy recommendations

1. Put in place the conditions necessary for Family Carers to receive regular and sufficient amounts of rest and time to self. Efficient respite services and home-based support targeted at both the needs of the Family Carer and care recipient have a significant role to play in making sure that Family Carers receive regular and sufficient amounts of rest, thus enabling them to continue in their role and having a positive health impact.
2. Introduce a full assessment of Family Carers' needs. There is an urgent need to recognise and address the needs of Family Carers in their own right alongside the needs of the care recipient in assessing care needs and allocation of care services. This would help to maintain the Family Carers' health and support them in their role. It is also important that the changing needs of the Family Carer are taken into consideration, as their role may dramatically intensify as the condition of the care recipient deteriorates. In the UK, the Carers (Recognition and Services) Act 1995 for the first time gave carers the right to an assessment of their own needs. In the absence of this being implemented by the Department of Health and Children and HSE in Ireland, The Parkinson's Association of Ireland could undertake a needs assessment of Family Carers of people with Parkinson's disease, while working in collaboration with organisations such as The Carers Association, who recently drafted a generic template.

3. Improvement of informal support mechanisms available to Family Carers. It is essential that the NGO sector work collaboratively in the provision of support services to Family Carers. For instance, working in partnership in the area of condition-specific training for Family Carers and in the area of condition-specific carer support groups in order to maximise Family Carer knowledge and skill base e.g. Carers Association and Parkinson's Association of Ireland. Reflection should also be given to current support groups where the Family Carer and care-recipient are present.

4. Introduction of a health promotion programme for Family Carers. In recognising the impact that caring can have on the health of the Family Carer, it is crucial that Family Carers are encouraged to look after their own health needs. One way in which this could be achieved is through a nationwide, comprehensive, annual check-up for all Family Carers. It is vital that equal emphasis is given to both the physical and emotional health aspects of caring. In addition, it is important to remember that Family Carers are not a homogenous group. It is envisaged that the Department of Health and Children would take responsibility for the roll-out of this programme.

5. Introduction of a public awareness campaign. There is an urgent need to improve awareness, understanding and recognition of Family Carers among the general public through a media campaign at national, regional and local levels. Specific examples of this include the ring-fencing of adequate levels of support for National Carers Week and the National Carer of the Year Awards, both of which should coincide with press and media campaigns by the Department of Social and Family Affairs to encourage take-up of Family Carer-related benefits.

6. Make education, information awareness and training of healthcare professionals in issues relevant to Family Carers' health a key priority. It is essential that all healthcare professionals have a comprehensive understanding of the role (and changing role) of the Family Carer in order to adequately address their needs. For instance, members of community health care teams such as the Public Health Nurse, Social Worker and GP should participate in modules on Family Carers as part of their training. In this regard, the NGO sector could take a proactive step in undertaking such presentations.
7. Establishment of an independent Family Carer 24 hour help line. There is an urgent need for an adequately funded and independent help line that Family Carers can access at any time of the day or night in a confidential manner.
8. Provide adequate services to support the health needs of Family Carers in the post-caring phase. The physical and emotional health consequences of caring may leave some Family Carers with serious difficulties coping with life after care, particularly for those who may have been caring for several years. Caring for a person with Parkinson's disease was viewed as a long-term role by participants in this study. There is also strong evidence to show that the psychological, social and physical health consequences of caring may leave some Family Carers poorly equipped for life after care (McLaughlin and Ritchie, 1994). Larkin (2009) found that many former carers' lives involve three distinct phases: the post-caring void, closing down 'the caring time' and constructing life post-caring. It is therefore essential that adequate support measures are put in place in order to improve the lives of Family Carers following their caring has ended. It is vital to first assess what the needs of former Family Carers are in order to highlight awareness among key healthcare professionals and NGOs.
9. All policy steps taken to support the health of Family Carers should be proactive rather than reactive. In many instances, and particularly in the case of Parkinson's disease, caring is a long-term commitment. Indeed the demands of the role intensify as the person's condition gradually worsens, thus impacting on the physical and emotional health of the Family Carer. It is therefore crucial that steps are taken to plan for the future support and health needs of Family Carers.

4.4 Opportunities for further research

1. Exploration of the health and well-being of long-term Family Carers from a post-caring perspective. Providing care to a family member may be a long-term commitment, lasting several years, particularly in the case of Parkinson's disease. Indeed, some Family Carers may have issues adjusting to life after care as caring may have serious physical, emotional and social consequences. Therefore, qualitative research exploring the specific needs of former carers may be warranted, particularly in identifying possible interventions that may have a positive impact.
2. Detailed investigation of Family Carers' relationships with healthcare professionals. This study highlighted the varied experiences Family Carers had with a range of healthcare professionals, with many highly critical of the support received. However, as this was not within the remit of this study, further exploration is warranted. For instance, it would be beneficial to investigate the factors that impact on Family Carers' experience of the relationship with healthcare professionals.
3. Examination of models of good practice of Family Carer supports in other countries. There is a case to be made for the preparation of a discussion paper on current supports available to Family Carers in other countries which in turn could be considered by policymakers and tailored to meet the needs of Irish Family Carers, thus improving their overall health and well-being.

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Appendix 1



Care Alliance Ireland

*The National Network of Voluntary Organisations for
Family Carers*

Information Leaflet

Project Title: The Caring Reality of Family Carers: An Exploration of the health status of a specific group of family carers

What is 'The Caring Reality of Family Carers' Study?

The Caring Reality of Family Carers study is an important new study of Irish Family Carers. The aim of the study is to explore the health status of a specific group of family carers.

The study will interview 20 family carers of a person with Parkinson's disease, focusing on their experiences and perceptions of their own health and well-being.

The study is being conducted by Care Alliance Ireland, in association with Parkinson's Association Ireland. Parkinson's Association of Ireland is a member organisation of Care Alliance Ireland.

Care Alliance Ireland

Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers. We aim to support organisations in their direct work of supporting Family Carers all over Ireland. We also provide information, education, and training, regarding the needs of Family Carers. We carry out research relating to Family Carers and promote interagency collaboration.



Why is this study important?

This study will attempt to give voice to family carers on issues regarding their own health and well-being. At the end of this qualitative piece of research, information will be available on the following

- Family carers' perceptions of factors which impact on their health
- Family carers' needs in relation to factors impacting on their health
- Any interventions which family carers can identify that would contribute to their health status given their particular circumstances

The research findings will shed light on Family Carers' current situation and will be used, along with previous work undertaken by Care Alliance Ireland, to lobby Government Departments for improvements in areas such as income support and health and social care services.

Why should I help?

In order to give a detailed account of the health status of Family Carers, it is important that you take part in this study, should you be caring for an individual with Parkinson's disease.

What does my participation involve?

Participation in the study will involve meeting with a fully trained and qualified researcher to hear about your own experiences of health and well-being as a Family Carer. This meeting is estimated to last between 20-40 minutes. It will take place at a time and place most convenient for you.

With your permission, the interview will be recorded. After the interview, the recording will be analysed. Your name will not be included in interview transcripts, an identity number will be used instead. All recordings will be kept in a secure place.

Individuals who take part in this research will be given a voucher in recognition of the time they gave to speak with the researcher for this study.

How was I selected?

You were selected due to your inclusion on the Parkinson's Association Ireland database; a large sample of individuals were chosen and sent information leaflets via post, inviting them to participate in this important study.

What about my privacy?

All information collected will be kept strictly confidential as required by law. Your identity will remain confidential and an identity number will be used instead. Your name will not appear in any report, paper or publication. Your identity will not be given to anyone. All information will be kept anonymous and confidential.

Will my caring payments be affected?

The financial assistance you may receive (be it Carers Allowance, Carers Benefit or both) for caring for your relative will not be affected, whether you choose to participate in the study or not.

Further Information:

Please feel free to contact Care Alliance Ireland if you have any further questions

The name of the main investigator, along with the telephone and email contact details is:

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Should you have any issues you would like to discuss in relation to Parkinson's disease, please contact the Parkinson's Association of Ireland free phone helpline on Ph 1800 359359

Appendix 2: Consent Form

Project Title: The Caring Reality of Family Carers: An Exploration of the Health Status of a Specific Group of Family Carers

All material gathered during this research project will be treated as confidential and securely stored. Please answer each statement concerning the collection and use of the research data:

I have read and understand the information sheet Yes No

I have been given the opportunity to ask questions about the study Yes No

I have had my questions answered satisfactorily Yes No

I understand that I can withdraw from the study at any time without having to give an explanation Yes No

I agree to the interview being audiotaped and to its contents being used for research purposes Yes No

I agree that I will not be identified from this interview and any subsequent publications (my name will be removed and my comments made unattributable) Yes No

I would like a copy of my transcript Yes No

I understand that all information collected in this study will be treated as confidential and my identity will remain confidential at all times Yes No

I freely and voluntarily agree to take part in this research project Yes No

Name of participant (printed) _____

Participant Signature: _____

Date: _____

Name of Researcher (printed) _____

Researcher Signature: _____

Date: _____

Please feel free to contact Care Alliance Ireland if you have any further questions

The name of the main investigator, along with the telephone and email contact details is:

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Appendix 3

Interview Guide

Project Title: The Caring Reality of Family Carers: An Exploration of the health status of a specific group of family carers

Opening Question:

- Tell me what life is like for you since you began providing care to X?

How has caring affected life:

- How has X having Parkinson's disease affected your life?
- Could you describe a typical day for you?
- What would a good/bad day be?

Current feelings on role as carer:

- How would you describe your role as Family Carer?
- How do you feel about caring for X?
- What do you feel is your contribution to X's overall care?
- What would you say are the challenges with caring with X?
- Do you feel your role as carer has changed over time?

Carer's health:

- How would you describe your own health?
- What factors do you see as impacting on your own health?
- Can you identify any interventions that you feel would contribute to your health status given your particular circumstance?

Impact on relationships:

- How would you describe your relationship with X at the moment?

- Would see any changes in your relationship with X since X developed Parkinson's?
- How would you describe your relationship with other family members/ friends since X developed Parkinson's?

Impact on self/ identity/ socialization:

- What would you say are your needs?
- Do you have any hobbies or interests?
- How would you compare your life now with your life before you began providing care to X? Are there any things that you miss doing that you used to?

Support

- Could you tell me what is your experience of support in your role as Family Carer?
- What techniques do you use to help you in your role as Family Carer?
- Have you received any training in your role as Family Carer?
- In your opinion, are there any gaps in the support you receive as Family Carer?
- Do you feel that your opinion counts, you are being listened to as X's Family Carer?
- What do you think would help you/ what types of support would be helpful, in your role as carer?

Feelings on the Future/ Worries:

- Do you worry, if so about what?
- What do you think would happen if you weren't able to care for X?
- What do you feel the future holds?

Appendix 4

Demographic Information Sheet

Project Title: The Caring Reality of Family Carers: An Exploration of the health status of a specific group of family carers

1. **Participant Code:** _____

2. **Gender:** Male Female

3. **Age:** _____

4. **Relationship to cared for person:**

Parent

Parent in-law

Husband/ Wife/ Partner

Child (under 18)

Adult Child (over 18)

Sister/ Brother

Grandchild

Neighbour/ Friend

Other, please state

5. **Where do you live?**

Urban location

Rural location

6. **Are you living with the care recipient?**

Yes No

7. **Who do you live with (apart from care recipient)?**

8. **Are you the person who provides most of the care?**

Yes No

9. How long have you been providing care (in months/years)?

10. Please state the primary medical condition and any other secondary conditions that the care recipient has?

11. How many hours of care would you say you provide in:

One day One week

11. Do you provide physical care?

Yes No

12. Would you receive periods of rest/ time to yourself? If so, please state:

13. Are you:

Single

Married

Widow

Widower

Separated/ divorced

Other, please state

14. Do you have children?

Yes No

If yes, how many: _____

15. Are you working outside of the home?

Yes No

16. If yes, please state your occupation:

17. If working outside of the home previous to taking on the caring role, please state occupation:

END