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# The Psychosocial Impact of Parkinson's Disease on the Wider Family Unit: A Focus on the Offspring of Affected Individuals

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## 1. Introduction

The psychosocial effects of Parkinson's disease (PD) on those affected by the condition are well documented (e.g. Calne et al., 2008; Frisina et al., 2008; Morley et al., 2007a; Ravina et al., 2007; Schrag et al., 2003; Slawek et al., 2005). A significant body of literature has also emerged investigating the impact of PD on affected individual's spouses and carers (e.g. Carter et al., 1998; Dyck, 2009; Lökk, 2008; Morley et al., 2007b; O'Connor & McCabe, 2010; Schrag et al., 2006). Perhaps surprisingly however, the impact of parental PD on the psychosocial adjustment and quality of life of both young and grown up children has, until recently, received little attention. Although Parkinson's disease is commonly regarded as a disease of the elderly a significant number are diagnosed before the age of fifty, and in approximately 5-10% the condition is apparent prior to age forty (Clarke & Moore, 2007). There is, therefore, the potential for children of a range of ages, young to adult, to be affected in a variety of ways by their parent's condition.

Previous studies focusing on children's response to a range of parental conditions and disabilities identify a number of recurrent themes. For example, children report elevated levels of depression and anxiety (Black et al., 2003; Forehand et al., 1988; Somers, 2007; Visser-Meily, et al., 2005; Yahav et al., 2007). Additionally, many experience changing roles and heightened responsibility (Caton et al., 1998; Strunin & Boden, 2004; Yahav et al., 2007). The provision of information for children regarding their parent's condition is also frequently raised (Caton et al., 1998; Cross & Rintell, 1999; Mukherjee et al, 2002). Previous studies also indicate that not all parental conditions affect children similarly. For example, some have suggested that children of parents with spinal cord injury appear well-adjusted to their parent's condition (Alexander et al., 2002; Buck & Hohmann, 1981). Additionally, children of parents with inflammatory bowel disease report some positive as well as negative responses to their parent's condition (Mukherjee et al, 2002).

The aims of this chapter are to present the emerging body of literature that focuses specifically on the impact of parental Parkinson's. The development of a questionnaire, the Parental Illness Impact Scale, (Schrag et al., 2004a; Morley et al., 2010a) to measure this impact has significantly aided research and allowed the field to move forward from earlier qualitative work. The development of this questionnaire is briefly outlined in the coming chapter. Research that has followed indicates that the children of people with Parkinson's

(PWP) can be affected in a number of ways. Evidence highlights potential difficulties in areas such as emotional well-being, changing roles, concerns for the future and relationships with friends. A number of these factors appear associated with key demographic variables such as a child's age or the duration of their parent's Parkinson's (Schrag et al., 2004b; Morley, 2008). There is also evidence that certain family structure variables may be implicated in children's response to their parent's condition. For example, research indicates that children without the support of siblings show inferior adjustment to parental illness when compared to those with brothers and sisters (Morley et al., 2010b). Issues surrounding sources of support and the provision of information for children regarding their parent's condition are also frequently raised (Schrag et al., 2004b; Morley et al., 2005; Morley, 2008; Morley et al., 2011). Emotional well-being has also been assessed and children of PWP appear at heightened risk of depression when compared to the normal population (Schrag et al., 2004b; Morley et al., 2005; Morley, 2008). Over the coming pages these research findings will be discussed in greater detail, and the chapter will conclude by discussing limitations in current research and making recommendations for future investigations.

## **2. Early research investigating the impact of parental Parkinson's**

The report compiled for the United Kingdom Parkinson's Disease Society by Roger Grimshaw (1991) was, to the best of the author's knowledge, the first to focus specifically on the offspring of parents with Parkinson's disease. As the first of its kind the importance of this work should not be underestimated, particularly in light of it being a catalyst for later research. In his research Grimshaw took a qualitative approach and focused on the perspectives of pre-adolescent children aged 5-12, and young people aged 16-24.

The work of Grimshaw (1991) built on a number of factors identified in previous research with families of those affected by chronic illness and disability such as that by Thurman (1985) and Rolland (1988). Such factors included, for example, the examination of styles of communication and those resources upon which families are able to draw when dealing with change. The research of Thurman and Rolland placed emphasis on the differing stages that individuals and families pass through, and also on the importance of gaining insight into how changes have specific impact at particular points in the lives of both parents and their children. Grimshaw, however, extended this and identified the need to view childhood as an 'active and responsive phase' in an individual's social development. Furthermore, he suggested the family is set in a far wider social context, as a 'social institution concerned with dependence', be that in relation to the elderly, the sick or more junior members. That a sense of obligation on the part of children to parents arises as a consequence of this 'social arrangement' is regarded as a foreseeable outcome. The equivalent concern of parents in not becoming a burden to their offspring is similarly viewed. In viewing the family unit in such a manner, Grimshaw postulated that it is important not to disregard aspects such as the gender of individual members and the affect this might have on how each might respond. Similarly issues of ethnic variations between families, the role of material circumstances, and accessibility of appropriate services are all areas that need to be taken into consideration. The final report of Grimshaw highlighted a number of pertinent factors when children are confronted with parental Parkinson's. These included children's changing roles, both domestic and emotional, within the family of a parent with PD, as well as relationships with both the well and unwell parent. Clear issues regarding children's social and emotional development and well-being, their level of independence, perceptions of disease, and fears for the future were documented.

The data collected by Grimshaw was qualitative in nature and achieved via family case studies through semi-structured interviews. This approach aimed to gain a greater understanding of the processes through which parents and children react to change and then develop new ways of living. Importance was attached to concentrating not solely on the negative experiences of children, but also on displaying how their experiences and perceptions uncover a variety of issues that have been confronted, some successfully, others less so. However, as Grimshaw himself acknowledged, a qualitative approach does not allow generalisations to be made regarding outcomes for a broader population. The qualitative nature of this research is therefore a major limitation, as is the selective nature and small size of the sample, which consisted of just thirteen participants. A major challenge for investigating this area further therefore was the development of a tool that allowed for greater generalisation and the work of Grimshaw proved to be a catalyst for further investigation into the impact of parental Parkinson's.

### **3. Development of the Parental Illness Impact Scale (PIIS)**

The Parental Illness Impact Scale (PIIS) evolved as a direct result of the previously discussed findings of Grimshaw (1991), firstly in an attempt to expand on this work, and secondly to take a quantitative rather than qualitative approach in investigating the impact of parental Parkinson's. The PIIS has been central to recent research, the findings of which will be discussed in a later section. Here the aim is to briefly outline the development and validation of the scale which to date has been subject to two major phases.

#### **3.1 Initial development and validation of the PIIS**

The initial development of the PIIS (Schrag et al., 2004a) was based on the qualitative data generated by Grimshaw (1991). Through a basic content analysis of the findings of this study, the original PIIS was constructed around a quality of life (QoL) model. As a concept it is generally agreed that QoL is multidimensional in nature, and is composed of differing domains. For example, one model of QoL put forward by Felce and Perry (1995) proposes the five principle dimensions of physical well-being, material well-being, social well-being, development and activity, and emotional well-being. Such dimensions are generally reflected in most models and regarded as significant in how an individual perceives their own QoL. It is worth noting however that despite the many advances in QoL research, there is still a degree of disagreement and no overriding consensus on a universally agreed definition (Dijkers, 2007; Moons et al., 2006). Recently there has been a move towards the inclusion of spirituality, religion, and personal beliefs as an additional dimension (O'Connell & Skevington, 2005; WHOQOL SRPB Group, 2006), although it has been suggested that this requires further investigation due to difficulties in its measurement (Molzhan, 2007; Moreira-Almeida & Koenig, 2006).

The preliminary version of the PIIS was comprised of 75 questions, 53 answerable on a 5-point Likert scale, and a further set of 22 dichotomous questions focusing on the provision of information and support. The questionnaire was administered to 89 children of parents with Parkinson's disease and subjected to psychometric analysis resulting in a questionnaire of 60 items, 38 answerable on a 5-point Likert scale, and 22 dichotomous questions. The authors concluded that the instrument demonstrated adequate psychometric properties. A number of limitations were identified, in particular weaknesses in the method of item generation, the self-selecting sample and the relatively small size of this sample. It was also recommended that the instrument be further validated with children of alternative parental conditions.

### 3.2 Further development and validation of the PIIS

The second phase of development of the PIIS aimed to address a number of the limitations of the original instrument as well as incorporate the recommendations of Schrag et al (2004a). The revised PIIS (PIIS-R; Morley et al., 2010a) was subject to a number of recognised procedures in the development of scientifically sound questionnaires. Key informant interviews and a literature review were conducted to ensure all relevant themes were incorporated in the revised instrument. Pre-testing was conducted through a 17 member expert panel and cognitive interviews with eight adolescent and adult children. The revised instrument was administered to 169 children of people with Parkinson's disease, multiple sclerosis and stroke, and subsequently subjected to a psychometric analysis. An outline of the structure of the PIIS-R along with reliability coefficients is given in Table 1.

Subscale	Number of Questions	Reliability (Cronbach's $\alpha$ )
Burden of Daily Help	8	.84
Emotional Impact	4	.83
Social Impact	6	.83
Communication & Understanding	7	.75
Impact on Personal Future	3	.84
Friends Reactions	3	.79
Parent / Child Relationship	3	.56
Global Well-Being	3	.73
PIIS-R Total	37	.92

Table 1. The Revised Parental Impact Scale: Outline Structure

The item reduction technique of principal components analysis was performed and resulted in 8 subscales, comprised of 37 items. The revised instrument showed good concurrent and discriminant validity through correlations with established measures of quality of life and psychosocial well-being. Internal consistency (Cronbach's  $\alpha$  .92) was high, and test-retest reliability values for subscales ( $r = .58 - .78$ ) and total score ( $r = .78$ ) were moderate to high. Whilst these results suggest the PIIS-R is a robust tool with which to measure the impact of parental illness, the authors acknowledged that a number of limitations still remain. The sample was again self-selected due to the mode of recruitment, and therefore responses on which the development of the PIIS-R was based may not have been representative of the target population. The sample was also largely of White-British origin, and therefore the reliability of the scale needs to be further assessed in alternative community samples. The authors also recommended that analysis of the psychometric properties of the PIIS-R continue with further administration, preferably in even larger samples. Longitudinal data would also provide the opportunity for further properties, such as predictive validity and sensitivity to change, to be assessed.

### 4. Current research findings

The administration of the PIIS and PIIS-R in conjunction with other validated questionnaires has generated the first quantitative data assessing the potential impact on children on having a parent with Parkinson's. This section summarises key findings in relation to QoL

and emotional well-being that should be of relevance to both clinicians and service providers, as well as provide some direction for future research.

#### **4.1 Quality of life**

As previously stated, the PIIS and subsequent revised version were constructed broadly around a QoL model. Studies to date indicate that the QoL of the offspring of parents with Parkinson's can be affected in a number of ways and dependent on a number of key factors, and particularly a number of demographic variables which are outlined below.

##### **4.1.1 Age of child**

In the first quantitative assessment of offspring of PWP, Schrag et al. (2004b) reported significant associations between children's age and a number of factors relating to QoL as measured by the PIIS. Results suggested that the younger the child the greater their perceived burden of daily help, and the greater the degree of difficulty in relationships with friends. Conversely, and as might be expected, the older the child the greater the recognition of the effects of PD on both their well and unwell parent. The authors of this study also make comparisons between a group aged 12-24 and those aged 25 and above, the results largely supporting the associations reported above. The younger sample reported a significantly heightened sense of burden in relation to their contribution to daily help in the parental home. As might be expected they also reported far greater difficulty in dealings with friends. The older sample reported a significantly heightened impact on family functioning.

Morley (2008) further assessed associations between age and QoL incorporating the PIIS-R. Results confirmed those of Schrag et al. (2004b) in relation to perceived burden of daily help and relationships with friends. Findings also suggested that the perceived impact on children's personal future increases as they get older. This is perhaps unsurprising since, with increasing age, children may become progressively more aware and realistic about their parent's condition. They are also better equipped educationally and emotionally to deal with the realistic prospects of their parent's condition (Lewandowski, 1992). What this data highlights is that children may require different types of support at different ages, and this needs to be considered in the management of their adjustment to parental Parkinson's.

##### **4.1.2 Parental disease duration**

Schrag et al. (2004b) reported a reduction in overall QoL as parental disease duration increases. Such a pattern was also evident in three particular subscales of the PIIS. Longer disease duration was associated with worsening communication and understanding, reduced development and independence, and increased impact on family functioning. Morley (2008) reported similar findings with longer disease duration again associated with inferior communication and understanding and deteriorating parent / child relationships. Such results reflect the progressive nature of PD and its impact on the child and highlight the need for ongoing support as the parental condition advances.

##### **4.1.3 Sibling support**

To the best of the author's knowledge just one study to date has focused on the availability of siblings as a factor in adjustment to parental neurological illness. Morley et al. (2010b) assessed the importance of sibling support within the family unit on adolescent and adult

children's response to parental Parkinson's, multiple sclerosis (MS), and stroke. Participants without siblings reported significantly greater emotional impact, elevated social impact, inferior communication and understanding with their affected parent, and heightened concerns for their personal future, as measured by the PIIS-R (Morley et al., 2010a). Total QoL scores were also significantly lower for children without the support of siblings. It is reasonable to speculate that these results reflect an inability to access support from siblings. This fits well with the Compensatory Siblings Hypothesis (Boer et al., 1992) where siblings use each other as a resource to make up for deficiencies in the parent-child relationship. This theory, however, is controversial and is contradicted by the Congruence Hypothesis (Sanders, 2004). Consistent with social learning theory the Congruence Hypothesis' contends that it is positive interactions between children and their parents that fosters positive interactions between the siblings themselves.

Results from this study should be met with a degree of caution. Although a sample of 168 adolescent and adult children participated, only 16 were 'only children'. Additionally, participants came from a range of parental neurological conditions and there are, therefore, limitations as to what can be concluded specifically in relation to parental PD. The results, however, stress the importance of recognising that children without the support of brothers or sisters may be at greater risk of responding negatively to their parent's condition, and this should be considered in the management of family adjustment to the parental condition.

#### **4.2 Availability of information and support**

The PIIS and the revised instrument incorporate a number of dichotomous questions focusing on the availability of support and information. Schrag et al. (2004b) reported that more than half of their sample (53.9%) felt they did not have enough information about PD, with an even greater proportion (67.4%) feeling they did not know enough about what would happen to their parent as their Parkinson's progressed. Nearly half of all participants (49.4%) felt that more information would lessen feelings of uncertainty and insecurity, with the same percentage relying solely on their parents as a source of information about PD. Morley (2008) reported similar results with 37.5% feeling they did not have enough information about their parent's PD and over half (53.8%) not knowing enough about what will happen to their affected parent in the future. This study also found 61.1% relying solely on their parents as a source of information about PD. These results and those of previous studies with alternative parental conditions (i.e. Caton, et al., 1998; Cross & Rintell, 1999; Mukherjee, 2002) emphasise the need to have appropriate and accessible information available for children of all ages of parents with PD.

Regarding provision of help Schrag et al. (2004b) reported 69.7% of participants wanting greater levels of help from local services, and 48.3% feeling it would be helpful if they had some influence over help provided. Of those families who participated in the study 55.1% had outside help available to help care for their parent with PD. Only 40% of families had access to support from local services, whilst approximately 60% thought more support should be provided. Again, Morley (2008) largely mirrors these results with 61% feeling greater levels of help should be provided by services and 40.5% suggesting it would help to be able to talk to relevant services about the care provided for their affected parent. Just 40.8% of families were receiving external help. Such results highlight the need for services to firstly be available where required and secondly to engage with affected families regarding the level and nature of their provision.

### **4.3 Emotional well-being**

Emotional well-being has been assessed in two studies to date, with both indicating elevated levels of depression in the offspring of PWP compared to levels in the general population. Incorporating the Beck Depression Inventory (Beck et al., 1961) for adults and Birlson Depression Self Rating Scale (Birlson, 1981) for adolescent participants, Schrag, et al. (2004b) reported 17.2% of 12-24 year olds and 21.7% of participants aged 25 and above as mildly to moderately depressed. Morley (2008) reported 12.5% of adolescent and 17.7% of adult children experiencing mild to moderate depression. Prevalence of depression in adults in the general population is estimated at 5%-10% (Singleton et al., 2003) and in adolescents at 4%-8% (Hazell, 2002; Son & Kirchner, 2000). As has been reported in other studies, the key to the effective treatment of depression remains its recognition and treatment in both adolescents and adults (Rowe et al., 2004; Kessler et al., 1999). It is therefore important that children confronted with parental PD, be they young or adult, are recognised as being at increased risk of mental health problems, as is supported by the levels of self-reported depression reported in studies of alternative chronic progressive conditions such as multiple sclerosis (Pakenham & Bursnall, 2006; Steck, et al., 2006; Yahav, et al., 2005, 2007).

## **5. Future research**

The following section attempts to identify current limitations and some key areas for future research that should facilitate further recognition of the impact of parental Parkinson's, help in developing practical strategies to assist in its management and inform the development of evidence based guidelines.

### **5.1 Longitudinal study**

There is a limit to what can be concluded from cross-sectional studies such as those currently undertaken with children of parents with PD. Longitudinal study is required in order to assess families over time and follow the course of social, emotional, physical and practical adjustment. This is particularly important with chronic progressive conditions such as Parkinson's, as it is likely that the impact on the child and the pressures they face, such as the decision to leave home, will become more profound as their affected parent's condition advances. A longitudinal approach might also highlight differences not evident from current cross-sectional studies. For example, current data shows minimal differences between males and females in their response to parental PD. Research suggests, however, that females rely emotionally on their parents more than males (Moore, 1987), and it may be that the impact of parental PD has a greater impact on females over time. As their parent's condition deteriorates emotional support is likely to be less forthcoming and the parent themselves may rely on the child for some of their emotional needs. Longitudinal study would also provide an avenue for the development of interventions, as well as the identification of those families and illness groups most 'at risk'. Despite significant advances in understanding a range of parental conditions, only in the assessment of parental affective disorder has longitudinal study made a significant contribution to the literature (i.e. Beardslee et al., 1993; Weisman et al., 1997), although important new longitudinal data is emerging regarding parental stroke (Sieh, et al., 2010; van de Port et al., 2007). Longitudinal research should therefore remain an important priority for those investigating parental PD and alternative conditions.

### **5.2 Comparative data**

There is a limit to what can be concluded from current studies of parental PD in the absence of comparative data from adolescent and adult children with healthy parents. Few studies across a range of parental conditions have incorporated control groups to date, although some recent studies, such as those investigating adolescent children of parents with cancer (Harris & Zakowski, 2003), and adolescent children of parents with multiple sclerosis (Yahav et al., 2005, 2007) have done so. This is another challenge for future research in this field. In the absence of control groups it is difficult to draw firm conclusions on a number of issues which are of importance when assessing the impact of parental illness.

### **5.3 Assessment of younger children**

There is a further need to assess the impact of parental PD on younger children, and not solely adolescent and adult children. Although the numbers of these children are likely to be small, the implications for children below the age of 11 are likely to be just as profound, if not more so, than for older children. Support groups and workshops, such as that provided for younger children of parents with cancer (Greening, 2009) and multiple sclerosis (Mutch, 2005), may well be a valuable tool in helping younger children understand what is happening to their parent with Parkinson's. Such groups allow children to meet with other children confronted with parental illness and encourage them to discuss their fears and emotional concerns in a supportive environment. Additionally, they can be provided with information to help them better understand the nature of their parent's condition.

### **5.4 Assessment of alternative groups**

There remain further important demographic factors and groups that need to be addressed in a comprehensive examination of factors influencing the QoL of children with Parkinson's. The need to examine different cultures is an important issue (Grimshaw, 1991). In doing so it is important to recognise that different cultures may require very different support. This is particularly so for those cultures where a far greater emphasis is placed on the social support network of the family. A comparison between ethnic minority groups and their support needs, and those of more individualised Western cultures would be an informative line of research. A further, and likely highly significant group currently not assessed are single-parent families where the parent is chronically ill, this being of particular relevance to the caring role played by children (Becker et al., 1998). The importance of investigating this group is further highlighted by research that has shown that child and adolescent rates of mental disorder are twice that in single parent families when compared with two parent families (Meltzer et al., 2000).

## **6. Conclusion**

This chapter has presented the emerging body of research investigating adolescent and adult children's response to parental Parkinson's. It is hoped that it has highlighted the potential needs of these children and that these needs should not go unrecognised. There is, however, much further research to be done. The needs of younger children have yet to be assessed and longitudinal study will facilitate the development of effective interventions and information resources. Such research will help to inform evidence-based guidelines. The recognition of the needs of the offspring of PWP is lacking in current clinical guidelines for

PD due to lack of research evidence. This is in stark contrast to other chronic conditions such as MS, where a significant body research has allowed the needs of children to be included in relevant guidelines (Morley et al., 2011). It is therefore vital that further research should become a priority if we are to adequately meet the needs of children touched by the effects of parental Parkinson's.

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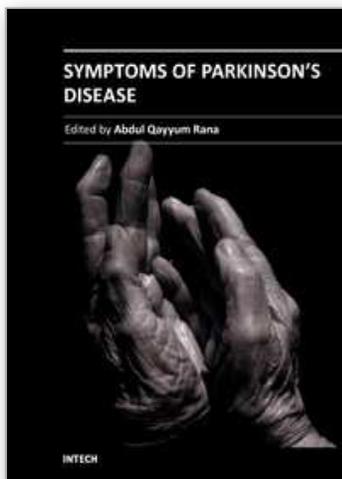
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## **Symptoms of Parkinson's Disease**

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This book about Parkinson's disease provides a detailed account of various aspects of this complicated neurological condition. Although most of the important motor and non-motor symptoms of Parkinson's disease have been discussed in this book, but in particular a detailed account has been provided about the most disabling symptoms such as dementia, depression, and other psychiatric as well as gastrointestinal symptoms. The mechanisms responsible for the development of these symptoms have also been discussed. Not only the clinicians may benefit from this book but also basic scientists can get enough information from the various chapters which have been written by well known faculty.

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