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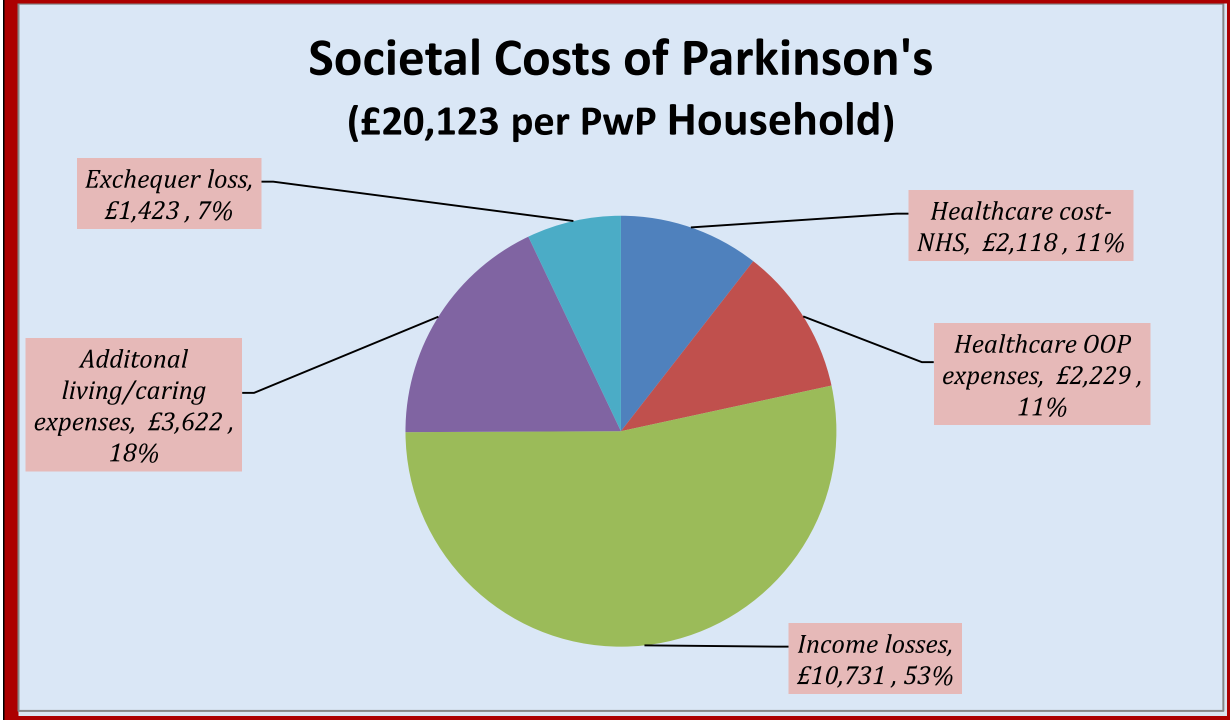
Economic, Social and Financial Cost of Parkinson's on Individuals, Carers and their Families in the UK

Executive Summary



Submitted By: Dr Anil Gumber
Centre for Health and Social Care Research (CHSCR),
Sheffield Hallam University,
Montgomery House,
Collegiate Crescent,
Sheffield,
S10 2BP
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Research Team

Anil Gumber (Principal Investigator)
Bhanu Ramaswamy
Rachel Ibbotson
Mubarak Ismail
Oranuch Thongchundee
Deborah Harrop
Peter Allmark
Abdur Rauf

Our Gratitude to the Project Advisory Group Members

Parkinson's UK
Laura Cockram, Eleanor Green and Laura Conn

NHS Specialist Nurse Invitees
Lucy Partington, Tracey Watts, Debbie Nash, Dot Hardyway

Our Special Thanks to the CHSCR Admin Team

Elizabeth Flower and Susan Dodd

This study is dedicated to all People with Parkinson's and their Families, with a special 'thank you' to the many people who contributed to this project. Their thoughts, openness and honesty have enabled us to gain greater insight into the costs of Parkinson's than previously understood.

Executive Summary

Introduction

The trend towards rising numbers of (older) people diagnosed with long-term conditions, such as Parkinson's in the United Kingdom (UK) continues. To address the needs of the currently estimated 127,000 people with Parkinson's the Government has to be responsive to the direct financial expenditure for commissioning health and social care services, and to understand how the condition will affect society as a whole.

This report details the main findings of research conducted through a survey of people affected by Parkinson's looking at health and social care costs incurred during the past 12 month period. The data is enriched by five in-depth interviews with people with Parkinson's and their caregivers who responded to the survey, providing a longitudinal view of their lived experience of the condition from the time around diagnosis up till the time of interview.

The survey questioned key accountable and non-accountable costs relating to the quality of life and wellbeing of the respondents, economic and financial costs, plus their utilisation of health services. Although many of the survey respondents lived alone, the majority were older and married, so 'the household' in the context of this study refers to a mean average size of 2 people.

The findings from the interviews allows for a view of the less tangible costs, such as the psychological impact, in addition to specifics of social and financial strain to the individuals, their family and to society as their Parkinson's has progressed.

The research implications are summarised into recommendations for implementation by those who write policy from a national health and social care perspective, and to those in the voluntary sector considering the support needs of people with Parkinson's.

The research and main findings

The study was undertaken largely utilising Parkinson's UK resources to seek responses. The profile of respondents mirrors the membership of the charity; largely white, married (with mainly female spouses in the role of caregiver), and with qualifications beyond GCSE. Whilst most people are over 65 years and retired, the age group of respondents from this study is younger than those involved in most studies, with people in the earlier stages of Parkinson's than in the literature reviewed. The responses were received mainly from England (80.3%), then Scotland (11.2%), Wales (5.5%), and Northern Ireland (1.2%), with only 5% people from ethnic minorities.

Not all sections of the 853 returns were filled. As each survey requested information about people with Parkinson's as well as their carers, analysis has been conducted on available data from up to 776 people with Parkinson's and their 546 carers. Where appropriate, a further breakdown into the four Home Countries has been performed in the main report. In some cases however, the low number of responses received from individual countries make further breakdown of figures unrepresentative of the population. In these cases, the figures are presented at aggregate level.

The research findings of the survey have been organised into four categories, with information from the five in-depth interviews adding salient comments to help understand aspects of living with Parkinson's that illustrate the figures, or that are harder to account for. The interviews utilised a conceptual social framework developed by a group of people affected by Parkinson's for a different study providing a perspective that counters the negative, linear medical model to consider strategies utilised by people as the condition progresses. Other qualitative information received from individual questionnaires has been considered as additional material in the Appendices, and will be analysed more fully as a separate account.

- **Direct and indirect health service costs**

A high proportion of people with Parkinson's continually used NHS services to consult professionals during the past 12 months (e.g. GP, neurologist and specialist nurse; in total 22 consultations), to undergo investigations e.g. blood tests or scans, obtain medication or acquire large pieces of equipment/health care packages. Other NHS costs included emergency and unplanned hospital admissions for people with Parkinson's, especially in the later stages, spending longer in hospital once admitted than the non-Parkinson's person.

Private payment was used for items not easily or regularly accessible through the NHS, e.g. sessions with podiatrist/chiropodists, chiropractors, optometrists or physiotherapists, small equipment such as mobility aids or pill timers, and also for out-of-pocket expenses such as travel and parking to health venues. For example, one of the interviewees, MA, pays for private chiropodist visits as podiatry in the local hospital was only available every four to six weeks, and he requires management at least monthly, stating: '*... and even in between then I'm suffering*'.

Things like physiotherapy and exercise might be through private means e.g. specialist clinic, leisure centre or subsidised through Parkinson's UK.

There was a £1,285,354 cost to the NHS and £161,920 for out-of-pocket expenses over the past 12-month period for those who completed the survey. This averaged out to £2,388 direct healthcare costs per person with Parkinson's. Taking into account out-of-pocket expenses towards travel and equipment purchased, the total annual healthcare cost per person with Parkinson's elevated to £4,347.

- **Social care costs**

Households with people affected by Parkinson's paid towards alterations in accommodation to adapt to changes in mobility conditions, or even moved from their previous home, most of which were self-financed capital expenditure. The changes were not easy, with some people feeling forced into the situation as can be seen in MA's statement about his move:

> '*I'm now in a bungalow because I couldn't manage the stairs where I was before. So I've moved into a sheltered housing... At first I wasn't going to accept this property because I thought oh it's going to be too small, too cramped, but I felt well yes I can't carry on where I am now...there was a risk of me having a fall [steep stairs]... So I had to really bite the bullet and say well my health is not, is obviously not going to get any better, it's only going to get worse. So I need to not only think now but look ahead to the future. ...but it was a case of I had no choice. It's something I had to do because I couldn't have continued where I was*'.

Other costs included payments for daily living assistance such as personal care, transport to appointments or shopping, house cleaning and gardening. Additional utility (mainly energy) costs and use of takeaway or ready meals added to their expenses.

Some of the social care costs were accessed through the local authority, but much came from family or out-of-pocket expenses of the people affected by Parkinson's. The total annual mean out-of-pocket expense was estimated at £3,622 per household that included a person with Parkinson's.

- **Societal costs**

Societal costs were noted mainly in terms of productivity loss arising from altered working patterns, with nearly one quarter of households reporting reduced monthly income. Parkinson's directly impacted on employment and working conditions, with half those diagnosed, and one-third of family members decreasing their working hours, seeking more manageable or adaptable positions, or giving up work completely.

The interviews permitted an insight into the psychological costs of oncoming symptoms, even prior to diagnosis. For example, MA, self-employed to install and service hands-free kits in cars for mobile phones, or radio systems stated:

> '*I noticed when I was doing installations that I was having problems sort of feeding cables through small gaps whereas previously I would've done it say in a matter of a few seconds. It would take me several minutes to do the same thing. Because I didn't seem to be able to, I didn't have the dexterity in my hands. Using tools was becoming more difficult…I would have to give myself longer on the job which isn't always a good thing…You've got a limited amount of time to do it so it increased the pressure on me as well'.*
>
> '*As a result the business was starting to suffer. I ended up having to sell my house because I couldn't afford the mortgage…I eventually had to give up self*-employment *and I then when to work for my local authority'.*

For CC, it was his loss of concentration and inability to word-find on tours he was guiding at the museum he worked at that affected his work prior to diagnosis.

Survey data calculated on an average a working person with Parkinson's lost 62.1 workdays per annum as a consequence of having Parkinson's, with caregivers losing on an average 18.9 workdays annually. Working persons with Parkinson's also reduced weekly hours by 12.4 and this reduction for caregivers was 10.7 working hours per week. This worked out to an average annual loss of £1,981 per household for those who continued to work. One in three people with Parkinson's were forced to take early retirement, or unable to work due to illness/incapacity or looking for a job adaptable to the needs of their Parkinson's. This accounted for annual earnings loss of £6,013 per household. Several informal caregivers were not enrolled with the Department for Work and Pensions for carer allowance, thus they were providing unpaid care to people with Parkinson's. This resulted in an annual earning loss of £1,235 per household. A considerable number of PwP and carers experienced discontinuance of their state benefits and pensions resulting in an additional loss of annual income of £1502 per household. Thus, direct and indirect annual employment earnings/income loss totalled £10,731 per household.

Utilising early retirement figures of people with Parkinson's and their carers, it has been calculated that the working lifetime earnings loss to a person affected by Parkinson’s who takes premature retirement at any age averages £43,170 per household.

- **Quality of life and wellbeing issues**

The majority of respondents with Parkinson’s noted a decline in their health status over the year, compared with about half of the carers (adding to their task of managing basic household needs), and only a third of people with Parkinson’s reported their health status as good or very good, with up to two-thirds reporting a need for help with activities within and outside the house. Compared to the general population of their age, this was observed in lower quality-adjusted life years (QALY) and mean wellbeing scores (life-satisfaction, life worthwhile, happiness and anxiousness) in carers, but more so in people with Parkinson’s, worsening in those who had been diagnosed for longer.

One of the in-depth interviewees, LA, noted her fatigue issues in an interview, affecting her enjoyment of her occupation as a Greenspace officer (project-work spread her working hours differently each day).

> ‘*...Because I kept irregular hours, I’ve always eaten my dinner late. If I was working in the evening I would have a snack late afternoon/teatime before I went back out to work and then I’d come back in after work and have my main meal then. I’ve noticed a big difference being off since October because I’m now eating at more what would be described as regular times’*.

There was also some fear expressed of facing a potential future that affected participation in activities with the local support group for Parkinson’s. LA’s account is a common issue in people with progressive conditions:

> ‘*And the reason for that [non-attendance at meetings, although a member of Parkinson’s UK] is I have a fear of meeting people who are at a much more advanced stage of Parkinson’s, which I could potentially be as well. I mean they’re all different, as you’re probably aware, everybody with Parkinson’s is different and quite unique, so there’s no saying how it will go, but it’s just the fear factor of seeing somebody*’.

The social framework highlighted the positives that kept people well, and socially or politically engaged; for example, those involved in the local Parkinson’s UK branch network gain from their contributions. Hence in an interview with AL and his wife, who have become the organisers of events for their local Parkinson’s group, AL notes:

> ‘*…I think a lot of the phone calls I get, people contact me because I’m the name in the... I’m the one that organises, and we go to the odd forum, and Parkinson’s has become my life really’*.
>
> AL’s wife adds: *‘Actually if we want to talk about expenses, financial yes, but the actual benefit from belonging to the Parkinson’s group and being the coordinator I think outweigh all of that. I think they’ve been extremely important*’.

There is pride in contributions individuals make to the charity impacting on their wellness, e.g. in his interview CC proudly recounted raising £1,200 in a sponsored walk for the charity.

Where markers of independence are lost, e.g. AL noted:

> *‘...Last week DVLA took the licence away on medical grounds…so where we’ll be taking buses and taxis and the like, so there will be expenditures on that*’, people approach it with pragmatism or humour: *‘...But then again we won’t have to insure the car*!

The interviews were able to add a perspective of the impact of priority changing behaviour. Some lessening life quality e.g. alterations to holiday destination to ones closer to home (a financial saving on travel, but increased insurance prices), transport or hotels that cannot always accommodate needs (psychological cost from stress of planning), creating fewer opportunities for people to go out with friends and associates (social costs), but for others creating gains from new social sets.

Conclusion

From the completed surveys by people affected by Parkinson's, this study was able to calculate an annual health and social care cost of Parkinson's to society by adding direct (mainly NHS) and indirect (mainly out-of-pocket) healthcare costs, non-healthcare expenses (paid for by the households), employment earnings losses (including unpaid caregiver earning loss), and cuts to benefits or pensions since registering with the Department for Work and Pensions as an elderly, disabled person or carer. The total societal cost was £20,123 per household, and excluding the NHS costs and exchequer loss, the annual direct financial burden on a household affected by Parkinson's averages £16,582. As the majority of households receiving gross annual income under £30,000, the direct financial impact of Parkinson's on their household budget was enormous. Monetary impact in terms of reduced income and savings and increased borrowings including mortgage equity release was the most felt; this was followed by the changed priorities for spending, reduced social activities and holidays and reduced spending on festive gifts.

The survey questions yielded over 750 variables for analysis. There is a strong message that as the condition progressed, and as people aged, whether diagnosed with Parkinson's or caring for someone with the condition, life quality and finances undergo a reduction.

The results have yielded recommendations for policy making based on improved understanding of the economic and social consequences of Parkinson's, the main ones being:

- That policy makers resolve inconsistencies in the provision of services, and funding accessible to people with Parkinson's across the UK. This includes consideration of identified work-related and benefit-related issues, impacting on households due to the Department for Work and Pensions, and Local Authorities regulations.
- The development of a positive, empowering model to achieve the social policy drive whereby people with long term conditions share management, including acknowledged support available from non-health resources such as voluntary organisations.
- Finding means that enable people living with, or affected by Parkinson's to remain independent and well for as long as possible through consistent provision of health and care services from diagnosis across the health, social care and independent sectors
- To commission investigation into longer term societal and human capital costs, studying the needs of people newly diagnosed, right through to those in the advanced stages of the condition, and their support networks.