The DDA a necessary, but not sufficient safeguard for people with progressive conditions in the workplace? The experiences of younger people with Parkinson’s disease.

Maggie Lawrence, Glasgow Caledonian University
Banks Pauline, University of the West of Scotland
The Disability Discrimination Act, a necessary, but not sufficient safeguard for people with progressive conditions in the workplace? The experiences of younger people with Parkinson’s disease

PAULINE BANKS¹ & MAGGIE LAWRENCE²

¹Health Qwest, School of Health Studies, Bell College, Hamilton, ML30JB, and ²NMAHP Research Unit, Glasgow Caledonian University, Glasgow, UK

Accepted March 2005

Abstract

Purpose. This study explored the impact of Parkinson’s disease (PD) on employment from the perspective of affected individuals. Particular attention was paid to factors that may affect the duration of employment after onset/diagnosis.

Method. Data were collected in two phases, i) a postal survey (n = 339), and ii) one to one interviews (n = 24).

Results. Four out of five participants reported that PD had made work difficult for them, only 15.3% had worked for more than five years post-diagnosis at the time of the survey. Several participants reported having experienced considerable stress prior to leaving work. Factors that precipitated withdrawal from the labour market included severity of symptoms, lack of support in the workplace, and opportunities for ‘early retirement’. Factors associated with maintaining employment included age at diagnosis, support received from employers, and manipulation of drug therapy.

Conclusions. It can be very difficult for people with PD to continue in paid employment for more than a few years post diagnosis. The relatively low level of contact between people with PD who were in employment and health professionals suggest that employment retention is not seen as major role for this group of professionals. There is a need for positive action to support people with progressive conditions in the workplace.

Keywords: Parkinson’s disease, disability, employment, rehabilitation

Introduction

Disabled people of working age are much more likely to be out of work than non-disabled people, and in the 1998 Green Paper, ‘New Ambitions for our Country: A New Contract for Welfare’ [1], the Labour Government set out its position on both social security and employment, the overall aim being “to increase both the proportion of people with disabilities who are in the labour force, and who are in employment, thereby producing beneficial effects to both disabled people and the wider economy and the welfare budget.” The links between unemployment, poverty, and poor physical and mental health are widely recognised, and the government believes that, for people of working age, employment is key to economic security and social inclusion. In recent years, in all industrial societies, there has been growing concern about the number of middle aged and older workers leaving the labour market as a result of illness or disability [2–4], and the government has introduced a range of policies designed to support job retention, and re-entry to employment wherever possible. These policies are based on a mixture of anti-discrimination legislation, tax incentives, and support provided through disability related programmes under the auspices of Jobcentre Plus. This paper presents the findings of a study which explored the impact of a progressive neurological condition, Parkinson’s disease (PD), on employment from the perspective of affected individuals, the aim being to gain some insight into the way in which current policy supports people with a progressive neurological condition.
Background

Although PD is often associated with older adults it also affects younger people, approximately 24,000 people with PD (PwPD) in the UK are below the age of forty [5]. PD is a chronic, progressive disorder of the central nervous system with characteristically insidious onset. Motor, cognitive and/or affective functioning may be effected and symptoms may include poor gait, micrographia, and quiet speech [6–8]. Mood changes are a major feature of PD’s, with depression being particularly prevalent [9–11]. One prevailing theory was that depression is a person’s ‘natural reaction to the disabilities imposed by their illness’ [12]. However, more recent evidence suggests that depression is part of the PD’s process itself [13–15], and may even be the first clinical manifestation of PD’s in some patients [16]. Diagnosis and treatment of depression is now seen to be an essential element of the management of PD’s [10,17–19].

The disabling effects of PD can be reduced or limited with drug therapy. However, although the majority of people with PD (PwPD) find their symptoms improve with the introduction of levodopa-containing drugs, it is usually necessary to increase the dose over time in order to maintain the improvement [5]. All the currently available drugs have been found to be problematic in some way—either in terms of side effects or because of the onset of complications as a result of taking the medication over prolonged periods [7,20]. Even with the help of drugs, symptoms can fluctuate considerably within a very short space of time, and PwPD follow a strict regime in order to maximise their function. Fluctuations in response to long-term levodopa therapy ultimately give rise to what is commonly termed the ‘on-off effect’ which is extremely disabling [7,12]. The effect occurs without warning, is unpredictable, and renders the PwPD ‘frozen’ and unable to move [21]. Dyskinesias may also occur and require supplementary drug therapy or invasive surgery to control them.

Due to these drug-related considerations specialists may suggest that drug treatment is withheld until symptoms cause significant problems. In particular, younger people may wish to delay initiation of levodopa therapy for as long as possible. Thus the clinician needs to discuss the potential medication regime as age at onset, gender and (projected) lifestyle are all crucial factors in the decision making process and various strategies are possible [7,12,15]. Surgical interventions may also be used to control symptoms.

PwPD benefit from the expertise of a range of allied health professionals including Physiotherapists, Occupational Therapists, Speech and Language Therapists, and Nurse Specialists [12,22]. In recent years many areas in the UK have established PD-specific multi-disciplinary teams. However, despite the increased provision many people are only seen as a result of a crisis [23], and access to multi-disciplinary teams is often restricted to people with advanced PD rather than those in the earlier stages [24].

Employment

The majority of disabled adults become disabled whilst in employment [25,26] and as people live longer and chronic diseases become more prevalent, it is to be expected that an increasing proportion of the workforce will experience disability [27]. Disabled people are twice as likely to be unemployed as people without disabilities, for example the Labour Force Survey (Winter 2001) [28] revealed that only 39% of disabled people in Scotland were in work compared to 81% of non-disabled people.

In the UK, as in the USA and Australia, strategies to encourage disabled people in the Labour market view employment as a civil right and have encouraged employers to address barriers that may hinder participation. This compares to a number of European countries where quota systems remain central to employment policy relating to disabled people. The Disability Discrimination Act (DDA) 1995, introduced with a view to ending the discrimination disabled people experience, replaced the post-war quota system in the UK. The first employment rights and rights of access were introduced in 1996, further rights were introduced in 1999, and 2004. The Act now covers all employers with the exception of some sectors of the armed forces. The recent Disability Bill 2004 has additionally placed an obligation on public bodies to be proactive in employing people with disabilities.

The DDA 1995 makes discrimination on grounds of disability unlawful. Under the Act PD is classified as a ‘progressive condition’, thus PwPD must not be treated less favourably than someone else because of their disability. This applies to recruitment and retention of employees, promotion and transfers, training and development, and dismissal. Employers have a duty to make reasonable adjustments to an individual’s employment or working environment in order to accommodate their needs. However, research focusing on the implementation of the DDA has produced mixed findings. A recent review [29] revealed that, while the number of cases taken under the employment provisions of the DDA had risen from 115 cases per month in 1997 to 442 cases per month in 2002/2003 many cases failed, and the process was found to be highly stressful for both employer and applicant.
Government concern about job retention has led to the development of a number of initiatives for example, the Department of Work and Pensions sponsors a range of programmes intended to help disabled people and/or those with a long-term illness to retain or re-enter employment (e.g. NDDP, Work Preparation, Workstep, Access to Work). However, these services often fail to connect with health services, and do not take a holistic view of clients’ support needs [30]. A report published by the British Society of Rehabilitation Medicine [4] noted that in the preceding 20 years unacceptable gaps had arisen between employment and health agencies in terms of the provision of rehabilitation services. Whilst health has focused on acute services, rehabilitation has been taken over by employment, creating difficulties for people who need support from health services to re-enter the labour market.

When a person becomes disabled they have to make adjustments, including coming to terms with the nature of their disability [31,32]. Their attitudes towards disability, self-image, health beliefs and the importance of work to them as an individual will all affect their response to their new situation [33]. Although PD is a progressive condition, not all those affected will experience the same symptoms, or the same rate of progress, and some will respond differently to treatment [10]. While many people will elect to remain in their current employment for as long as possible, a chronic degenerative disorder such as PD will inevitably result in a decline in work ability as the symptoms worsen [34], and affected individuals may have to choose from a number of options.

The ability to work more flexible hours has been found to benefit to employees with disabilities [35–37] and may be helpful to PwPD whose work-related performance is determined by their drug regime. There is evidence to suggest that some occupations offer greater scope for accommodating difficulties experienced by disabled people [38], and people with disabilities may be offered (re) training, usually on computer courses or relating to other Information and Communication Technologies (ICT) [37,39], which may lead to a change in role within the same workplace, or enable individuals to seek alternative employment. However, some disabled job seekers report that employers are not willing to ‘take the risk’ of employing a disabled person [40]. Furthermore, some PwPD have been found to be loath to tell employers of their diagnosis for fear of being misunderstood or asked to retire, or fear of discrimination [37]. Research has shown that 61% of people who acquire a disability whilst in employment eventually leave because of the attitudes and behaviours of their peers [25,41].

Self-employment has been promoted for disabled people because it allows flexibility regarding tasks, working hours, and targets. However, although a self-employed person may be able to work from home, thus avoiding problems associated with transport, self-employment requires high levels of energy and motivation and should not be considered an ‘easy option’ [37].

A recent study focusing on disabled workers’ experiences in the workplace [42] found that disabled workers used a diverse and often complex range of strategies to enable them to cope, and that individual differences e.g. nature of employment, time in post, financial environment, meant that strategies that worked for one person might be unhelpful or risky for another. Interestingly they found that much of the support that was valued by employees was ‘informal’ in nature and thus vulnerable to staff turnover or changes in working practice. The study concluded that while many people had overcome significant barriers to gain and retain their positions, a number of participants were nonetheless surviving rather than thriving.

Making choices

Chronic illness such as PD invariably affects other family members [43]. People in younger middle age typically have busy lives; some may be considering starting or adding to their family, others will have older children and be reliant on dual incomes to fund further or higher education, spouses/partners may have their own work commitments, and some may have caring responsibilities for elderly parent [44,45]. While current policy promotes employment as a route to social inclusion and economic security, it is important to note that the government’s position is ‘work for those who can, security for those who cannot’. Thus, it is accepted that for some people paid employment may not be possible, or be very difficult, for a variety of reasons. Younger PwPD may find that achieving a balance between different facets of their lives entails difficult decisions.

While we acknowledge that the experiences of PwPD will differ in a number of ways from people with other progressive conditions, we believe that many of the barriers and concerns encountered by participants in this study will be experienced by others who experience the onset of disability in adulthood.

The research

The study described here sought to explore the impact of PD on employment from the perspective of affected individuals. Particular attention was paid to factors that may affect the duration of employment after the onset/diagnosis of PD, including factors within the workplace and healthcare. Discussion
focuses on the benefits and drawbacks associated with current policy which emphasises the benefits of employment.

**Methods**

*Data collection*

Data were collected using both a postal survey and one to one interviews. Questionnaires were distributed through the Parkinson’s Disease Society using a variety of methods: i) Questionnaires were sent to PwPD on the Young Alert PD Partners and Relatives group database (YAPP&Rs), a special interest sub-group of the PD Disease Society, ii) A small number of PD disease nurses (PDNS) distributed copies of the questionnaire to PwPD of working age with whom they were in contact, iii) an invitation to take part in the study was published in the PDS magazine *The Parkinson* and the YAPP&Rs magazine. The final question in the survey asked participants if they would be willing to take part in a one-to-one interview—interviewees were selected on the basis of gender, employment (working/not working), and time since diagnosis (< 1 year, 2–5 years, 6+ years). Ethical approval was granted by the MREC for Scotland.

Interviews were recorded and fully transcribed. Transcripts from the interviews and qualitative data derived from open-ended questions in the survey were entered into NUDIST for analysis, which involved both thematic and content analysis. Quotations are included to illustrate specific points and are not necessarily representative of the experiences of other participants. Figures in brackets indicate the number of participants who mentioned a specific issue in response to an open-ended question.

**Results**

*Participants*

Three hundred and thirty-nine PwPD, who were either of working age (females ≤ 59 and males ≤ 64) or in paid employment at the time of the survey, 164 males, and 175 females, returned completed questionnaires. Because we were not directly responsible for distributing the questionnaires we were not able to calculate a response rate. Two hundred and forty-four participants were recruited through YAPP&Rs, 87 through PDNS, a further eight PwPD contacting the research team directly. The mean age was 54.6 years; the youngest participant was 27 and the oldest 75 (see Figure 1). Twenty-four PwPD, 11 males and 13 females, took part in the one-to-one interviews. The mean age of interviewees was 51.6 years. The youngest interviewee was 43, the oldest 61.

*Time since diagnosis*

It is not uncommon for PwPD to experience symptoms for some time prior to diagnosis. For the purposes of this paper we have chosen to focus on time since diagnosis, as it can be difficult for people to accurately recall their first symptoms. Just over half the participants (54.9%) reported having received a diagnosis within a year of initial symptoms (onset); a further quarter (22.1%) received a diagnosis within two years. However, some of the remaining participants reported that they had experienced symptoms for longer periods prior to diagnosis. Time since diagnosis also varied with a small number of participants (7.2%) having received their diagnosis within the year preceding the study. Just under half (47.7%) had received their diagnosis between one and six years prior to the study, and a slightly smaller number had received their diagnosis more than six

![Figure 1. Age and gender of participants (frequency).](image-url)
years prior to taking part in the study (44.2%). Age at diagnosis ranged from 22 to 72 years with a mean of 47.5 years. Almost two-thirds (65.5%) had received a diagnosis of PD aged 50 or less.

**Employment status**

One hundred and three PwPD (30.4%), 51 males and 52 females, were in paid employment at the time they completed the postal survey. Of those who were not in employment, 176 participants (74.6%) reported that they had retired because of PD, 16 had retired because of age, six for health reasons other than PD, 17 were homemakers, 15 were unemployed, and three carried out voluntary work. Eleven out of 24 PwPD who took part in the one-to-one interviews were in employment. The mean age of retirement amongst participants who had retired because of PD was 50.1 years; the mean age amongst those who reported that they had retired on the basis of age was 54.5 years. Nine participants were over pensionable age (60 + for women and 65 + for men), but were in paid employment at the time of completing the survey. Thus it can be seen that the concept of ‘working age’ is relatively fluid.

Twenty-three participants reported having left work prior to receiving a diagnosis due to symptoms that were subsequently linked to PD. Seventeen participants did not work following diagnosis due to the symptoms of PD, and a further 20 stopped within a year of diagnosis. Amongst participants who returned to employment post-diagnosis, and subsequently retired due to PD, the average number of years of continued employment was 4.9 years (standard deviation 3.5). Table I presents information relating to the employment status of participants by age, age at diagnosis, time since diagnosis, time since first symptoms, and gender.

**Age at diagnosis**

Amongst participants who had left work due to PD, there was a significant inverse correlation between the number of years worked and age at diagnosis \( r = -.536, p < .01 \). Participants who had been diagnosed at a younger age were found to have worked longer than those who received their diagnosis later in life. However, analysis of the qualitative data revealed that it was not a simple picture. A number of participants reported that their employers had operated a policy of retirement at age 60 irrespective of gender, others had been able to take advantage of early retirement packages that had been available to all employees, irrespective of health/disability status. Voluntary redundancy could become an attractive proposition:

> The company I worked for was offering redundancies with generous compensation, so I decided to leave in case forced redundancies with less generous terms were to be imposed at a later date.

Some participants indicated that the age of onset had an impact on their ability to cope with symptoms, for example if nearing retirement age, it was sometimes possible ‘hang on’:

> By retirement age [I was] just beginning to find some tasks, especially talking in public and managing a local government department, a little difficult.

<p>| Table I. Employment status by age, age at diagnosis, time since diagnosis, and gender. |
|-----------------------------------------------|-----------------|-----------------|-----------------|</p>
<table>
<thead>
<tr>
<th>In paid employment</th>
<th>Not in employment</th>
<th>Significance level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age</td>
<td>52.8</td>
<td>55.6</td>
</tr>
<tr>
<td>Mean age at diagnosis</td>
<td>48.6</td>
<td>47.0</td>
</tr>
<tr>
<td>Mean time since diagnosis</td>
<td>4.2 years</td>
<td>8.6 years</td>
</tr>
<tr>
<td>Mean time since first symptoms</td>
<td>6.2 years</td>
<td>10.5 years</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>31.1%</td>
<td>68.9%</td>
</tr>
<tr>
<td>Females</td>
<td>29.7%</td>
<td>70.3%</td>
</tr>
</tbody>
</table>

Analysis is based t-tests & chi-square.
However, another participant felt bitter about the lack of support received:

I could have continued to do my job – [I] only had 3 years [to go]. . . . no adjustments made, and the treatment from my employers. . . they harassed me out of my job.

Severity of symptoms

Analysis of scores derived from the SF36 revealed that, overall, participants experienced a marked degree of impairment (see Table II). Participants who had left employment because of PD had significantly lower mean scores on all eight subscales than participants who were in paid employment. However, it should be noted that there was considerable variation within the groups (std dev.), as well as overlap between those who were working and those who had left paid employment (range).

Overall 227 participants (81.5%) reported that the symptoms of their PD had made work difficult for them. When asked about the nature of the difficulties they experienced 104 participants reported that tiredness and a feeling of being slowed down were major problems. Seventy participants claimed that they had difficulty writing, and while some could overcome these difficulties by typing, 58 participants reported that lack of flexibility in their hands made both keyboard work and fine skills difficult to manage:

I was a full-time secretary – touch-typing became very difficult. . . shorthand and writing things down difficult, I found it very tiring. . .

Other difficulties reported included coping with a tremor (55), and impaired memory and lack of concentration (32):

I am much slower in thought and physical activity. Often confused/lack of concentration. Forgetful. Tremor gives difficulty in writing. . . Not really up to my job but still there.

Speech problems were an issue particularly when dealing with the public (25):

Speech being slurred and quiet, and difficulty finding the ‘right’ words to say.

Participants also reported difficulty walking (21), poor balance, and lack of co-ordination e.g. stumbling/ tripping (21), stiffness (18), pain (13), and visual problems (5). A number of participants drew attention to the psychological impact of their condition, e.g. inability to deal with stressful situations (26), increasing lack of confidence (16), anxiety or panic attacks (10), and depression (7). Others highlighted the difficulty of coping with fluctuating ability and ‘on/off’ periods:

I feel this disease is awful because when you have better days everyone thinks there is nothing wrong with you. They think you are putting it on when you say your legs ache etc. . . .

Coping with work was particularly difficult for PwPD who were self-employed, participants explained that they felt that they had to be fully able at all times:

I was self-employed and didn’t like meeting people because of PD. I was a painter and decorator and climbing ladders and driving became impossible.

Overall eleven participants mentioned difficulty driving which could affect their ability to work if their employment had involved driving, and travel-

Table II. SF36: mean scores by employment status.

<table>
<thead>
<tr>
<th>Sub-scale</th>
<th>In paid employment (n = 103)</th>
<th>Retired due to PD (n = 176)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (95% Confidence Intervals)</td>
<td>Mean (95% Confidence Intervals)</td>
</tr>
<tr>
<td>Physical Function</td>
<td>58.7 (24.9, 63.7)</td>
<td>35.1 (22.8, 38.7)</td>
</tr>
<tr>
<td>Role-physical</td>
<td>38.5 (23.6, 43.5)</td>
<td>14.9 (28.5, 19.5)</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>60.0 (24.6, 65.5)</td>
<td>44.1 (22.1, 47.5)</td>
</tr>
<tr>
<td>General Health</td>
<td>52.3 (20.5, 64.3)</td>
<td>39.0 (19.8, 42.0)</td>
</tr>
<tr>
<td>Vitality</td>
<td>42.4 (20.1, 56.4)</td>
<td>31.9 (20.0, 35.0)</td>
</tr>
<tr>
<td>Social function</td>
<td>66.8 (25.8, 71.9)</td>
<td>49.7 (24.3, 53.1)</td>
</tr>
<tr>
<td>Role-emotional</td>
<td>55.3 (25.8, 63.9)</td>
<td>43.0 (41.1, 50.0)</td>
</tr>
<tr>
<td>Mental Health</td>
<td>65.2 (19.1, 67.9)</td>
<td>58.4 (19.5, 61.4)</td>
</tr>
</tbody>
</table>

A high score indicates better health; analysis is based on t-tests.
ling to work if alternative methods were unsuitable or not available.

Nature of employment

In this study the proportion of PwPD that worked/had worked in manual jobs that reported that they had stopped work because of their PD (65.3%) was slightly higher than for those who had worked in non-manual jobs (47.9%). However, this difference failed to reach the required level of significance. There was no difference in duration of employment post-diagnosis amongst those participants who had retired because of PD associated with nature of employment.

Leaving employment completely is not the only option for people acquiring an impairment or progressive condition. Eleven participants (3.2%) reported that they left a job to look for more suitable employment. Although five of those who had sought alternative employment were working at the time of the study, PwPD reported that they found it difficult to secure another job citing severity of their symptoms, and/or inability to cope with the stress of interviews. Other participants found that the main opportunities for re-training were in computer skills, which was not always suitable for people whose hands and/or speech were affected by their condition. One participant, a full-time employee, who had hoped to set up her own business, had abandoned the idea because she felt that she was no longer able to approach the banks for funding.

Just over one-third of participants (35.0%) reported that they had provided information about PD to their employer, and almost one in five (18.2%) had asked their employer to make adjustments to their work. A large majority of these participants reported that their employer had been supportive (73.8%). Analysis revealed that participants who reported that their employer had been supportive in helping them to overcome any difficulties related to PD, who subsequently left work, had worked for longer post-diagnosis (mean = 5.4 years) than those who did not think that their employer had been supportive (mean = 3.2 years) \(t(50) = 2.539, p = .014\).

Overall 52 participants, almost one in five of those who reported that their symptoms made work difficult for them (18.8%), reported that they had reduced their hours at work. Although two-thirds (65.4%) of those who had reduced their hours were in employment at the time of the study, it did not always provide a long-term solution and there was no difference in the duration of employment post-diagnosis amongst those who had reduced their hours prior to stopping work completely and those who had not:

I first reduced my hours because I was finding the work difficult to cope with and I was so tired. When this didn’t help I stopped working…

Some participants, including teachers, reported that they were unable to reduce their hours because of the potential impact on final salary pensions. Others acknowledged that altered hours could be difficult for employers:

My timing is a bit erratic. I have so many clinics and appointments with Doctors and physios etc; I am hardly there…

A number of participants (17) reported that their overall role and/or specific tasks had been changed. Other adjustments requested included less driving/travel, and the provision of equipment. In some cases requests for adjustments were turned down or participants felt that obstacles were put in their way. In other cases participants reported that their employers’ had been unable to help them:

I asked my employer if there were any lighter duties I could do, and was told that if I could not do the job I was paid to do, then there was no job for me.

Sixty-eight participants (24.5%) who had experienced difficulties at work reported that they had used some form of aid to help them complete work tasks. Of these, 26 had organised and paid for their own aids, 24 reported that their employer had organised and paid for their aids, and 13 had received support from by the Employment Service’s Access to Work scheme. The most frequently used equipment was enhanced computer equipment e.g. a laptop for taking notes, voice recognition software, modified keyboard or mouse. However, participants reported mixed levels of satisfaction; for example voice recognition in particular was not popular. There was no difference in the duration of employment post-diagnosis amongst participants who had stopped work due to PD associated with whether or not participants had used work-aids \(t(138) = .646, p = .520\).

Two participants reported that a full and detailed analysis of their situation had been undertaken, with a view to providing support in the future. However, in both cases, the time taken to write the report was considerable, and both participants had left employment before the recommendations were implemented:

[They] came up with this package of reducing my hours and they offered to provide me with a computer…

I never actually took up any of that because I left before…

[Image 489x15 to 599x29]
Few participants reported being aware that the DDA existed or, if they had heard of it, knew more than its name and/or believed that it would not be applicable to their circumstances. While employers would undoubtedly have been aware of the DDA, they did not always know that their employee had a diagnosis of PD or what the implications of such a diagnosis might be. A small number of participants reported that they did not wish to inform their employers of their condition thus denying themselves the opportunity to seek support:

I chose to be a ‘closet’ Parkinson. But the strain of hiding my symptoms and holding down a senior position was tremendous. My GP said I was killing myself.

Support received from health professionals

Almost three-quarters of participants (73.8%) reported that they saw their GP between one and four times a year, and more than half (55.5%) attended between two and four outpatient appointments annually. Just over one in five participants (22.9%) reported that they had been in contact with a multi-disciplinary team. There were no association between level of contact with GPs, the number of outpatient appointments, or having access to a multi-disciplinary team and duration of employment post-diagnosis amongst participants who had stopped work due to PD ($p > .05$). As can be seen from Figure 2, which shows the proportion of participants who had contact with a range of allied health professionals, psychological services, counsellors and district nursing, contact with a range of health professionals was low around the time of diagnosis and increased thereafter. Only one in five (20.0%) participants had contact with a PD Nurse at the time of diagnosis, and 56 (16.5%) had contact with a physiotherapist. Perhaps

the most notable aspect of the chart is the proportion of participants who had received no input at all from these health professionals.

Further analysis revealed that a slightly higher proportion of participants who had stopped work because of PD reported that they had had regular contact with physiotherapists, occupational therapists, district nursing. These findings suggest that allied health professionals may not see issues associated with employment as part of their remit.

Drug therapy

Overall 320 participants (94.4%) reported that they were receiving drug therapy. Of these, 201 (62.8%) reported that their drug therapy helped a lot, 101 (31.6%) that it helped a little, and 15 (4.7%) that it made no difference or made them feel worse. Participants who took part in the one-to-one interviews spoke of the difficulty of maintaining a balance between their medication and quality of life, drawing attention to side effects which could offset any benefits in terms of symptom control. Of those participants who were using drug therapy, a quarter (25.0%) reported that decisions relating to drug treatment had been influenced by how they thought it would affect their ability to work:

My drug treatment is specifically geared to enable me to continue to work.

The main ways in which drug regimes were modified were by increasing the dosage, either overall or just on working days, and the timing of doses. Respondents reported that they were taking higher doses of medication than they would if not working, and/or adjusting the timing of medication for maximum effect during working hours:

![Figure 2. Participant who had had contact with health professionals at the time of diagnosis, regularly as required following diagnosis, or had no contact (percentage).](image-url)
I probably am taking more than I would want to take if I wasn’t working - I need them to get through the working day more than when I am at home.

Amongst participants who had stopped work due to PD, those who reported that their decisions relating to drug therapy had been influenced by how they thought it would affect their ability to work had worked for longer post diagnosis (mean = 6.3 years) than those whose had not considered the impact on employment (mean = 4.3 years) \( t_{82} = 2.655, p = .010 \). Further analysis revealed that a higher proportion of PwPD who had received their diagnosis in their 30s modified their drug regime to enable them to work (50.0%), compared to those who received their diagnosis in their 40s (41.9%), or their 50s (35.7%). However, these differences did not reach the required level of significance \( p > .05 \).

There was a marked dichotomy between respondents who felt that work was of paramount importance in their lives, for example, one respondent regretted that he had not had sufficient information to enable him to keep working:

Did not know anything about the medications when first diagnosed, but if I had I would have chosen medication that allowed me to continue working as I am very 'work orientated'.

and those who were concerned about the longer-term impact of drug therapy. A number of respondents reported that they were trying to delay beginning drug therapy, while others were unwilling to increase their dosage due fears of the short term efficacy of drug treatments, and the potential for side-effects:

I was not prepared to medicate heavily and sooner than necessary in order to continue to work in view of the prospect of side effects from long-term drug use.

Several participants drew attention to the importance of achieving a balance in their lives:

I have taken, and still do take drugs that enable me to carry on with as 'normal' a life as possible, including being at work.

**Work/life balance: Accommodating other commitments**

The onset of a progressive disorder such as PD impacts on the whole family. Although it is often assumed that families will provide informal care, not all family members are in a position to adopt this role either for physical or emotional reasons.

While some family members became actively involved in researching PD and providing high levels of support other participants reported less understanding:

My husband thinks if we don’t talk about it, it will go away.

A number of interviewees reported having experienced varying levels of depression which hindered their ability to develop effective coping strategies, and had a negative impact on other family members. Participants highlighted the importance of looking at their lives as a whole rather than just focusing on one aspect of it, particularly when they fulfilled multiple roles:

I had 5 children at home aged 7 – 16 years at time of diagnosis.

The impact of disability on the family has been highlighted in the ‘younger carer’ literature. In this study 59 participants (17.4%), 27 males, and 32 females reported that they lived with children/young people aged less than 20, of these almost one in five (18.6%) were single parents. A further 45 participants reported that their adult children aged 20 plus lived with them—a proportion of these young people may also have been involved in further or higher education and thus still at least partially financially dependent.

‘Quality of life’ is not just about being able to work and the responsibilities of bringing up a family; leisure pursuits and hobbies are also valuable and, for many families, provide relaxation and a shared interest. A number of participants expressed bitterness about the fact that they would be expected to continue working until they were too disabled to be of any use to their employer:

I tried to make a case in the beginning for getting my pension on the basis that it was inevitable that I’d be ill, and why shouldn’t I have a couple of years out of [work] with a pension when I was relatively OK? . . . I didn’t get anywhere with that . . .

**Financial implications**

Retiring early has considerable financial implications for younger PwPD. Although a number of participants reported that they had managed to secure generous packages on leaving work, others were less fortunate:

[I was] subjected to bullying treatment by first line Manager. Signed off with stress—quit after several weeks with no pension etc.
Participants were asked how satisfied they were with their financial situation. Surprisingly, there was no association between satisfaction with ‘current financial situation’ and ‘employment status’. However, a higher proportion of PwPD who were in employment (46.6%) reported that they were worried that they would not have enough money in the future compared to those who had left work due to PD (34.9%) ($\chi^2 (2) = 6.706, p = .035$). Although the above findings seem intuitively wrong, discussions in the one-to-one interviews indicated that respondents who were working often wanted to work as long as possible in order to maximise their final pension and hopefully ensure financial security in later years. Several respondents commented on the stress of trying to continue to work.

### Discussion

Current policy promotes employment for disabled people who are able to work on the basis of social inclusion, better health, and quality of life. There is a substantial literature on the benefits of employment. However, it is important to note that employment can also have a negative effect on mental health. While work can bring advantages including financial remuneration in the short term, a pension in the longer term, social interaction, a structure to the day, intrinsic satisfaction and interest, for some people it may provide little more than a daily grind just above, or possibly below the threshold for welfare benefits. The effort involved in meeting productivity targets, travelling to and from work, and interacting with the general public and/or colleagues can be daunting for people living with a chronic condition.

This study has looked at factors that may have an impact on the length of time that PwPD are able to remain in employment including age at onset, severity of symptoms, nature of employment, support received from employer, support received from health professionals, and the use of drug therapy. Analysis showed that it can be very difficult for some PwPD to continue in paid employment for more than a few years post diagnosis; only 52 participants (15.3%) had worked for more than five years post-diagnosis at the time of the survey. Four out of five participants reported that PD had made work difficult for them. Several participants reported having experienced considerable stress prior to leaving work.

Although people diagnosed at a younger age worked for longer post-diagnosis than people diagnosed later in life, this may in part have been linked to opportunities for early retirement offered to people aged 50 plus that would have been available to all employees irrespective of health status. There was evidence of variation in the level of support and/or accommodation from employers, for example some participants were offered shorter working hours, greater flexibility, and a change in duties, while others received limited or no support. Participants who reported that their employer had been supportive were found to have worked significantly longer post-diagnosis than those who reported that their employer had not been supportive. While this finding is to be welcomed, it is important to bear in mind that few participants were aware that they were protected by the DDA, and only one in five had actually asked for any adjustments to their working environment. Furthermore, some instances support was put in place too late to be of value. While it would be hoped that the obligation to be proactive in employing people with disabilities enshrined in the recent Disability Bill 2004 will have an impact on the support available to disabled people in employment, it should be borne in mind that some employers might believe that there is a contradiction between retaining disabled employees and economic efficiency.

Participants who had retired because of PD were found to have significantly more advanced physical impairment, experienced more pain, greater tiredness, and had more severe emotional problems including depression. There was no evidence that frequency of contact with health professionals had an impact on duration of employment, however, the relatively low level of contact between PwPD who were in employment and health professionals suggest that employment retention is not seen as major role for this group of professionals.

Analysis revealed that PwPD who manipulated the timing and dose of their drug treatment to allow them to continue working, worked for longer than those who did not. However, it could be that the manipulation of drug therapy in this way was associated with a positive attitude to work, and that people with a positive attitude towards work would be more likely to work longer despite experiencing difficulties.

Finally we drew attention to the impact of a condition such as PD on the whole family; particularly those that included children aged less than 20, and financial satisfaction. Problems identified included communication within the family and lack of energy preventing participation in leisure activities. Analysis of the data relating to the financial impact of PD drew attention to the importance of perceived satisfaction rather than the size of income in absolute terms. While some participants spoke of the restrictions of final salary pensions, of not being provided with the support needed to enable them to work until ‘official’ retirement age, or being ‘forced out of’ their jobs, others were in a position to retire early and enjoy a few years of relatively good health, taking part in activities originally planned for later life.
The findings of this study raise a number of issues regarding employment and people with a progressive disorder, such as PD. Clearly, the provisions of the DDA are vital in order to address the discrimination that many disabled people face in the labour market. However, this level of support in itself is insufficient; people with progressive conditions need to be empowered to make ‘optimum’ decisions regarding continued employment bearing in mind the potential impact on their health, their families, and their employers. Both the DDA in its quest to eliminate discrimination, and the social justice agenda in its quest to promote social inclusion, take a unidirectional approach. They fail to accommodate the particular circumstances of individuals who have a degenerative condition that will, over time, impact negatively on their ability to work or carry out other activities of daily living.

We do not suggest that people with a progressive condition should not remain in paid employment as long as they are able. However, we do question whether or not all younger people with PD have access to adequate information to enable them to make an informed decision relating to continuing or leaving employment. Many people without disability approaching pensionable age have access to pre-retirement classes, advice on financial planning and ways in which to cope with what is perceived to be a major ‘life-event’. However, there is a dearth of support for younger people with PD, a group of people who are likely to stop work within a few years of diagnosis. In addition to current anti-discrimination legislation there is a need for the targeted provision of information and advice.

Acknowledgements

This research was funded by the Parkinson’s Disease Society.

References


33. Shaw L, Segal R, Polatajko H, Harburn K. Understanding return to work behaviours: promoting the importance of the individual perceptions in the study of return to work. Disability and Rehabilitation 2002;24:185–195.


