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Driving and Parkinson's disease: a survey of the patient's perspective

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Running Title: Parkinson's patients' perspectives on driving

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Abstract

Background: Parkinson's disease (PD) is a multi-system disorder that can impact on driving ability. Little is known about how these changes in driving ability affect people with PD, making it difficult for clinicians and carers to offer appropriate support.

Objective: To assess patient views concerning the effect of PD on their driving ability, the impact of these changes and how they manage them.

Method: An online survey was created by a team of clinicians, people with Parkinson's, their carers and representatives from Parkinson's UK. People with PD throughout the United Kingdom were invited to participate through Parkinson's UK's website, newsletter and Parkinson's Excellence Network email list.

Results: 805 people with PD took part in the survey. We found that the loss of a driving licence had an adverse impact on employment, socialisation, travel costs and spontaneous lifestyle choices. Multiple changes in driving ability related to PD were described, including that impulse control disorders can have an adverse impact on driving. Changes in driving ability caused people to change their driving practices including taking shorter journeys and being less likely to drive at night. Participants advised managing changes in driving ability through planning, vehicle adaptations, maintaining skills and self-assessment.

Conclusion: This study demonstrates the impact that changes in driving ability can have on the lifestyle of people with PD and reveals the strategies that individuals adopt to manage these changes.

Keywords: Parkinson's Disease, Automobile Driving, Impulsive Behavior, Quality of Life, Survey

Introduction

Parkinson's disease (PD) causes progressive decline in motor function resulting in bradykinesia, rigidity, tremor and postural instability. It can also be associated with a decline in cognitive function [1], visuo-spatial deficits [2], sleepiness [3], variable effectiveness of medications [3] and changes in decision making [4]. This myriad of symptoms is likely to impact on the ability to perform a complex motor and visual-spatial task like driving. Indeed, on-road and driving simulator studies have shown that, compared to controls, people with PD make more errors during manoeuvres and at traffic lights [5], have delayed decision making, use mirrors less effectively [6], have poorer reaction times and vehicle control [7, 8] and an overall deterioration of driving ability when presented with dual stimuli [9, 10]. As a result, people with PD may alter the way they drive. This includes reducing the distance and duration of journeys [3] and being less likely to drive at night or alone [5]. People with PD stop driving earlier compared to a control group adjusted for age, gender, education and miles driven per week [11]. As a consequence, their fitness to drive needs to be regularly reviewed [12].

Physicians and people with PD have both been found to be poor at predicting driving ability [13-15]. Perhaps with this in mind, a considerable focus of research has been to identify the best methods for physicians and allied professionals to assess a person with PD's fitness to drive [16-18]. No method of off-road testing has been found to be reliable in predicting driving ability in people with PD and the gold standard remains on-road assessment [16-18]. The majority of those with PD referred for driving assessment (perhaps, because of a concern regarding driving ability) have their licence removed, with cognitive impairment being the best predictor of an adverse outcome [19].

The loss of the ability to drive or being prevented from driving by a licensing authority can lead to depression [20], decreased activity outside of the home [21], social isolation [22] and more reliance on care givers [23]. The overall impact of not being able to drive on quality of life is likely to be significant. Understanding this impact is vital for developing appropriate guidelines for clinicians and providing suitable support for people with PD, yet there is relatively little literature available regarding

the perspective of people with PD. We looked to address this gap by asking people with PD about how their driving has changed since diagnosis and what impact this has had on their lives.

Materials and Methods

We created a survey for people with PD hosted online at SurveyMonkey® [24]. Questions were written after consultation with clinicians involved in the care of people with PD, people with PD and their carers and a representative from Parkinson's UK. The survey was piloted with the same group and changes made based on their suggestions. It was available for completion from 21st January 2017 until 18th June 2017. People with PD were invited to participate through Parkinson's UK's website, newsletter and Parkinson's Excellence Network email list. We estimate that 3000 people with Parkinson's would have had the opportunity to complete the survey.

The first section of the survey outlined the purpose of the survey and that results may be published. Participants were then given the option of proactively opting in in order to participate.

The survey structure is shown in supplementary file 1, with the full list of survey questions shown in supplementary file 2. Respondents who had never held a driving licence exited the survey after answering basic demographic questions only. Respondents who had not driven within the last three years only answered questions about the circumstances of losing their licence and the impact it had. Access to several questions in the survey was dependent on the prior answers given by the participants.

Free text responses to the survey were reviewed by two researchers (LO, PB). Thematic analysis of the data was performed [25]. Firstly, the researchers worked independently, reviewing the responses and identifying themes emerging through an inductive, iterative process [25]. The two researchers then met to compare notes. Themes were discussed, challenged and refined. Repeated reading and

discussion of transcripts continued until consensus was reached. This triangulation between researchers enhanced the credibility of the conclusions drawn.

Results

DEMOGRAPHICS AND EFFECT OF LOSS OF DRIVING LICENCE

Table 1 shows the demographics of the 805 people who completed the survey and their driving status. It also describes the impact on lifestyle that the loss of a driving licence had on the survey respondents. We found that the loss of a driving licence, be it voluntarily or following instruction from the UK licensing authority (DVLA) had an adverse impact on employment, socialisation, travel costs and ability to make spontaneous lifestyle choices.

COLLISIONS WHILE DRIVING

15% (n=104) of 672 survey respondents who had driven in the last 3 years stated they had been involved in a collision since being diagnosed with PD, of whom 15 respondents had two collisions and 2 respondents had 3 collisions.

CHANGES IN DRIVING FUNCTION AND STYLE

Respondents indicated that they experienced changes in driving function and style since being diagnosed with PD. Table 2 details the changes they have had in their functions related to driving since their diagnosis of PD and adaptations they have made to their vehicles.

Respondents were also asked to select ways in which they have modified their driving style since being diagnosed with PD. They could select all the changes that they had made and the results are detailed in Figure 1.

CONCERNS RELATED TO DRIVING

We asked if respondents had concerns about their own driving, 18% (n=95/528) said they did. 12% (n=65/542) of respondents had family or friends who had expressed concerns about their driving. In addition, 14% (n=90/643) of respondents had felt sleepy while driving and 16% (n=102/638) found spoken word programmes distracting while driving.

IMPULSE CONTROL DISORDER AND OFF TIME

Of the survey respondents 10% (n=69/688) had been told they had impulse control disorder by a healthcare professional and 2% of survey respondents (n=11/559) said that an impulse behaviour had an adverse effect on their driving, including speeding, driving when sleepy, taking unsafe short cuts and road rage.

47% of survey respondents (n=295/628) indicated that they suffered from wearing off of their medication. Of this group 41% (n=125/305) said they needed to fit their driving around their 'on' time, with a small number of respondents (n=8/277) saying that their 'on' time was not predictable enough to manage this safely.

TIPS FOR DRIVING FROM PEOPLE WITH PARKINSON DISEASE

From analysis of the responses to a question asking respondents whether they had any tips for driving with PD four themes emerged.

1. PLANNING

Respondents described the importance of planning journeys around the times of the day where traffic was minimal, avoiding night time journeys and ensuring the driver knows the route prior to setting off.

"Mentally rehearse the route that you are going to take beforehandit saves any confusion as you are approaching a junction or roundabout about which direction to take" Respondent 588

They also stressed that journeys should be planned around when medications are providing benefit and that breaks in journeys should be made to avoid missing tablets.

“Work out your effective time to drive. Adjust the medication times to suit your lifestyle. If you get signs of wearing off stop in a convenient safe place, take your tablet and rest” Respondent 205

2. VEHICLE ADAPTATIONS

Using automatic transmission, satellite navigation and higher cars for ease of access were all advised by our survey respondents.

“I would definitely encourage PD people to change to an automatic car. It is less tiring and so releases more energy to concentrate on other aspects of driving” Respondent 601

3. MAINTAINING SKILLS

Respondents gave advice to maintain driving skills by seeking driving tuition and assessment from Driving Mobility centres. They also advised maintaining physical and mental health, particularly by using puzzles or crosswords.

“Exercise helps to keep the neck mobile - essential for driving safely” Respondent 190

“Keep your brain active, maths, reading, crosswords, don't watch TV.....study the route and if required plan it” Respondent 291

4. SELF-ASSESSMENT

Respondents emphasised the need to assess your own ability to drive. This included prior to driving when making decisions about journey length and safety, but also while driving, noting when fatigue began and when medications were wearing off.

“Listen to your body! Don't drive if you are tired. Take frequent breaks on a long trip” Respondent

Discussion

Our survey captured the opinions of a large and varied sample of people with PD. It is the first to ask people with PD about the impact of relinquishing their driving licence. Adverse effects on employment, socialisation, transport costs and the ability to make spontaneous lifestyle choices were all identified. This is in keeping with the social isolation and decreased activity outside the home seen in people without Parkinson's who lose their ability to drive [21, 22]. It is notable that these problems arise despite the high proportion of people living with someone who can drive and the spread of rural, urban and suburban environments. Furthermore, these issues occur in a developed nation with access to subsidised public transport, social services and charity support.

Our results show that people with PD make a variety of changes to their driving style in order to accommodate the changes in function caused by their condition. The frequency of people having to take shorter journeys and avoiding driving at night suggests this too could have an impact on socialisation and lifestyle choices. To minimise these detrimental effects those involved in the care of people with PD need to optimise the ability of people with PD to drive safely and review whether their access to alternative forms of transport is sufficient.

The survey results highlight the impact of both motor and non-motor symptoms of PD on driving. In particular, it draws attention to the effect impulsivity can have on driving and suggests that people with PD should be counselled about this risk. Both the impact of wearing off and fatigue were emphasised by our survey respondents in their free text responses. Previous studies [3, 26, 27, 28] exploring sleep issues in people with PD also investigated respondent's propensity to fall asleep whilst driving. These studies also employed survey methods with 2 studies recruiting participants via a single centre, [26, 27], 1 study via multiple sites [28] and 1 study via their national PD Association [3].

Fatigue leading to dozing while driving was found to occur in PD [26, 28] and increased daytime sleepiness is a risk factor for sudden onset sleepiness while driving [3, 27]. The insight provided by this survey into how these problems are managed by people with PD could be used as a basis for advice provided by healthcare professionals. In particular, we call attention to the four themes of planning, vehicle adaptations, maintaining skills and self-assessment as a basis for realistic and practical guidance that can be given to people with PD.

We acknowledge the limitations of collecting data through an online survey. This method was chosen in order to gather data from a large number of people with PD. Completing the survey required internet access and the cognitive capacity to complete the task which could have limited its accessibility. The demographics detailed in Table 1 suggest the sample is representative of the PD population in the United Kingdom who do not have cognitive impairment. We acknowledge that the low number of people on cholinesterase inhibitors, and that we did not collect diagnostic data regarding cognition, means that we cannot be confident our data is representative of people with cognitive impairment. Not all participants completed the survey in full, which is demonstrated in the variable total respondents to each question in our results. We have no mechanism for verifying the accuracy of the responses given. The survey questions had not been validated against the medical records or objective driving assessment of those people with PD involved in the survey development. Studies in small groups of people with PD have shown a poor correlation between their self-estimates of their driving behaviour and their actual driving behaviour [16]. Former drivers generally underestimate the costs of running a car and this needs to be considered in relation to their response about transport costs. Recruitment of a control group was not undertaken as the surveyed population was too large for a reliable control group to be recruited. We did not use a validated tool for assessment of PD severity through an online survey so we are unable to draw correlation between the severity of a respondents PD and their driving outcomes with the data gathered.

Future research should look to provide insight into the impact that driving authorities, clinicians and the voluntary sector have on how people with PD change their driving practices. In addition, the impact that changes in driving ability can have on carers for people with PD is worthy of further study. Greater knowledge of these areas would allow healthcare professionals and driving authorities to better tailor the advice they provide about driving to people with PD and their carers.

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Conflict of Interest

The authors have no conflict of interest to report.

Ethical approval and consent

Northumbria Healthcare NHS Foundation Trust Ethics Review Board advised that formal ethical approval was not required for this study.

Participants were consented to take part in the study through a written statement at the beginning of the survey which explained the purpose of the survey and how the results would be used. They were required to select that they consented to the description in the written statement in order to begin the survey.

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Table 1: Demographics and driving status of survey respondents and the impact of relinquishing driving licence

Mean age		67 years (range 35-88)
Gender	Males	59% (n=474)
	Females	41% (n=331)
Time since Parkinson's diagnosed (n=726, mean=7 years, range 0-56 years)	0-5 years	48% (n=349)
	6-10 years	30% (n=217)
	11-15 years	15% (n=106)
	Greater than 15 years	7% (n=54)
Driving licence status (n=747)	Current licence holder	84% (n=629)
	Former licence holder	14% (n=105)
	Never had a licence	2% (n=13)
Additional vehicles to a car (n=41)	Minibus	7
	Lorry	4

	Van	17
	Moped (under 50cc)	3
	Motorbike (over 50cc)	10
Driving essential for work (n=675)	Yes	12% (n=82)
	No	25% (n=172)
	Retired	63% (n=421)
Home circumstances (n=621)	Lives alone	17% (n=105)
	Lives with someone who drives	73% (n=454)
	Lives with someone who does not drive	10% (n=62)
Personal care (n=528)	Independent	88% (n=465)
	Requires help	12% (n=63)
Home environment (n=665)	Rural	39% (n=259)
	Urban	29% (n=194)
	Suburbs	32% (n=212)
Symptom profile (n=630)	Significant memory problems	10% (n=59)
	Episodes of confusion	10% (n=61)
	Difficulty in concentrating	22% (n=132)
	Excessive sleepiness	22% (n=137)
Medication regime (respondents selected all that applied – n=510)	Levodopa preparation	85% (n=431)
	Dopamine agonist	50% (n=254)
	COMT inhibitor	15% (n=79)
	MOA-B inhibitor	38% (n=194)
	Anticholinergic	2% (n=10)
	Cholinesterase inhibitor	1% (n=7)
	Relinquished licence voluntarily	67% (n=64)

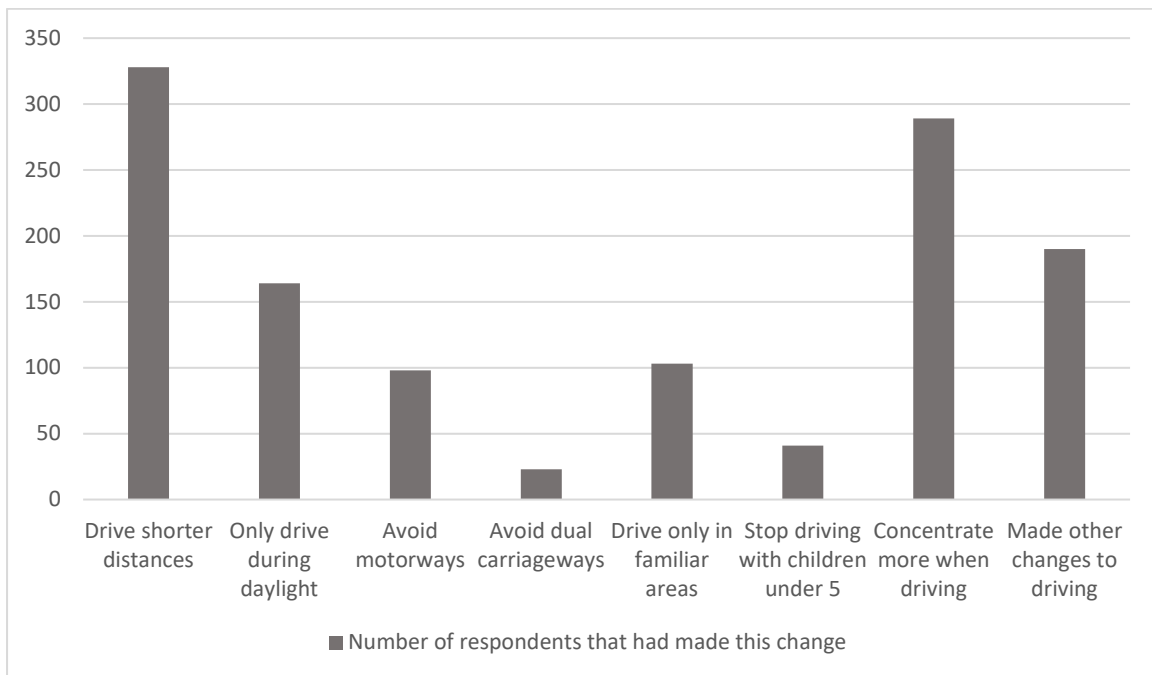
Respondents who have relinquished licence (n =95)	Licence removed by driving authorities	33% (n=31)
	Disagreed with decision of driving authority	61% (n=19)
	Appealed decision of driving authority	16% (n=5)
Since relinquishing licence (n = 95)	Had to stop working	7% (n=7)
	Less socially active	84% (n=80)
	Transportation costs increased	39% (n=37)
	Less spontaneous lifestyle choice	82% (n=78)

Table 2: Changes in driving style since diagnosis of Parkinson’s disease

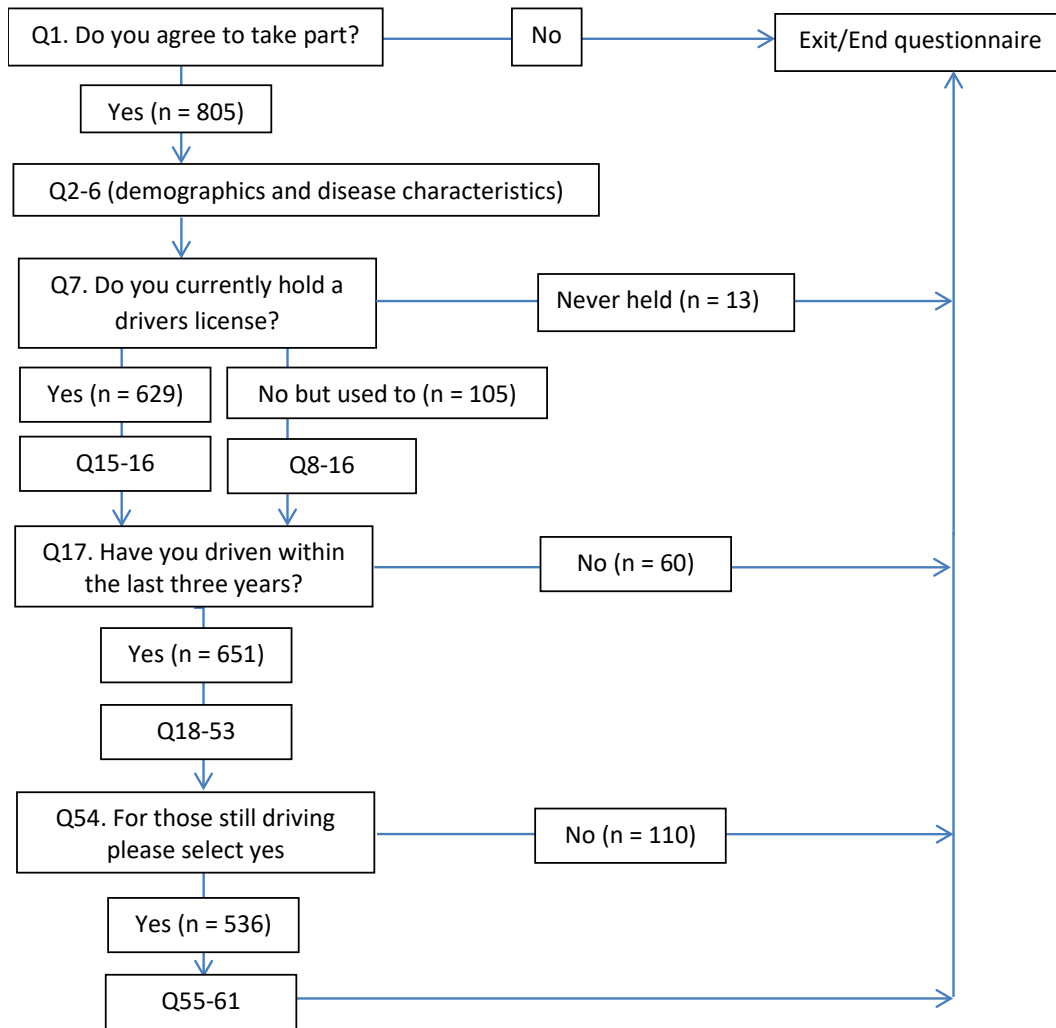
Since being diagnosed with Parkinson’s disease have you..	Respondents who answered ‘Yes’
Had changes in vision? (n=644)	22% (n=141)
Had changes in head and neck movement? (n=648)	33% (n=214)
Had difficulty judging speed and distances? (n=635)	19% (n=122)
Had difficulty with manoeuvres? (n=637)	41% (n=264)
Become lost more frequently? (n=625)	8% (n=47)
Had changes in your ability to drive safely? (n=636)	17% (n=130)
Changed or adapted your car? (n=657)	26% (n=169)
Adaptations made to vehicles (respondents could select all that applied)	
Automatic transmission	149

Hand Controls	2
Reversed foot pedals	5
Higher/larger car purchased	14
Smaller car purchased	4
Keyless entry/ignition	1
Parking sensor/cameras	4
Blind spot eliminator	1
Steering wheel adaption	2

Figure 1: Ways in which respondents have modified their driving style since diagnosis with Parkinson’s Disease



Supplementary Data 1: Survey structure demonstrating exit points



Supplementary Data 2: Full list of survey questions

1. Do you agree to take part?
2. Age?
3. Sex
4. In what year were you diagnosed with Parkinson's?
5. Are you affected on one side of the body more than the other?
6. Do you consider yourself to be right handed/left handed/ambidextrous?
7. Do you currently hold a driving license?
8. Did you stop driving voluntarily or was your licence removed by the DVLA?
9. If the DVLA removed your licence, did you agree with the decision?
10. Did you appeal against the decision?
11. Did you have to stop working when you relinquished your licence?
12. How has the loss of your licence affected your participation in social/leisure activity?
13. How much do you agree or disagree with the following statement: Since losing my licence my transportation costs have increased
14. How much do you agree or disagree with the following statement: The loss of spontaneity linked with the loss of my driving licence is an important issue for me
15. Do you currently drive?
16. Have you/your clinician informed the DVLA about your diagnosis- or are the DVLA aware of your diagnosis?
17. Have you driven within the last 3 years?
18. Were you advised to inform the DVLA at diagnosis by healthcare team?
19. How many times has your driving licence been renewed?
20. Was your car insurance premium increased after being diagnosed with PD?
21. Do you have a blue disabled badge?
22. If no, have you previously applied for one and been refused?
23. Do you live alone?

24. If no, does anyone who lives with you drive?
25. Other than a car, please select any vehicles that you currently drive (tick all that apply)
26. Do you/have you driven any other vehicles requiring more than a standard car licence?
27. Is driving an essential component of your work?
28. Have you driven vocationally (ie Professional driver - driving as your job)?
29. Where do you live? Please select the word that you feel best represents your area
30. Has your doctor or Parkinson's nurse ever told you that you have impulse control disorder?

[Impulse control disorder is sometimes linked to Parkinson's medication. It can cause impulsive or compulsive behaviours, increased sex drive, gambling, compulsive shopping, binge eating, obsessive interest in hobbies and risk taking behaviour.]
31. For current drivers, does impulsive behaviour currently affect your driving (eg taking risks)?
32. Has impulsive behaviour previously affected your driving (eg taking risks)?
33. Since being diagnosed with PD have you ever been involved in a collision?
34. If yes, how many times?
35. If yes, Was/were the accidents your fault? (Please detail each time - Yes / No / equal blame / Don't know)
36. Does your Parkinson's affect your ability to control your vehicle safely at times?
37. Have you changed your car / adapted your car due to your Parkinson's?
38. If yes, what type of adaptation (please tick all that apply)
39. Since being diagnosed with Parkinson's – has your vision been affected? Had your head and neck movement been affected? Do you have more difficulty judging speed and distances? Have you had more difficulty with manoeuvres such as parking? Have you had to adapt your style or method of driving?
40. Since being diagnosed with Parkinson's, have you changed your driving style? (please select all that apply)
41. When driving, have you become lost more frequently since you developed Parkinson's?

42. Do you find driving long distances a problem?
43. Do you feel sleepy whilst you are driving?
44. Do you listen to the radio / music / audio books or similar when driving?
45. Do you find spoken word programmes distracting when you are driving?
46. What do you listen to?
47. Do you get wearing off of your medication?
48. If yes, do you need to fit in your driving around your "on" time?
49. If yes, is your on time predictable enough to manage this safely?
50. Do you experience significant memory problems? Episodes of confusion? Excessive daytime sleepiness? Difficulty in concentrating?
51. Do you think it would be a good idea to have a limited area licence as, for example, in Scandinavia, where people with this licence are restricted to driving within, say 30 miles, of their home?
52. Do you have any tips that you have learnt in relation to driving that might be useful to other people with PD? Please state
53. Are there any other issues not mentioned in the questionnaire that you think are important?
54. For those still driving currently please select yes to answer the final few questions, and for those no longer driving please select no - these were the final questions. Thank you.
55. Current drug treatment (Please select all that apply) *For people taking Stalevo, please select both; Levodopa and Catechol-O-methyl transferase inhibitor
56. Do you have any concerns about your driving?
57. Has anyone in your family or a close friend expressed concerns about your driving?
58. Have you been asked to stop driving, eg by GP/consultant?
59. How many penalty points do you have on your license?
60. Do you experience any of the following (please select all that apply)
61. Do you need another person to help with your personal care?

