



Self-reported visual complaints in people with Parkinson's Disease

Emma van de Klundert

Master Thesis – Clinical Neuropsychology

S4588975
September 2022
Department of Psychology
University of Groningen
Examiner: dr. G. de Haan
Daily supervisor: drs. I. van der Lijn

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Abstract

Introduction: Visual problems are one of the underrecognized non-motor symptoms in people with Parkinson's disease (PD) in clinical practice, resulting in delayed diagnoses and further worsening of visual problems and quality of life. Since subjective visual assessments may provide additional insight into the patient's visual functioning, compared to objective measurements alone, the aim of this study is to investigate the spontaneously reported visual complaints (SvC) of people with PD, compared to controls. In addition, relations between SVCs and demographic and disease characteristics are investigated. Finally, this study examines the difference between SvC and reporting visual complaints on structured items.

Methods: A large cohort of people with PD (n = 581) and an age-matched control group (n = 583) have completed the Screening Visual Complaints questionnaire. This questionnaire starts with an open question about SvC, which is followed by 19 structured items regarding several visual complaints. *Results:* The most frequently reported SvC in people with PD were unclear vision, trouble reading, double vision and needing more light. More SvC were reported in people with PD than controls. People with PD with SvC were more likely to be women, had a longer disease duration, a higher disease severity and used a higher dose of medication than people without SvC. More visual complaints were reported on structured items than spontaneously by people with PD. *Conclusion:* Since people with PD report more SvC than controls and the visual complaints increase as PD progresses, it is important to repeatedly screen people for visual complaints. In addition, people with PD report visual complaints on structured items more often than spontaneously, making it important to ask about visual complaints in a structured way. However, it is also important to ask for SvC, as these can reveal additional complaints that would be missed by structured items alone.

Keywords: Parkinson's Disease, Visual Complaints, Vision Screening, Surveys and Questionnaires, Self report

Introduction

Parkinson's disease (PD) is a neurodegenerative disorder characterized by a dopamine deficiency in certain brain regions (Antal et al., 1998). As a result of ageing, PD is a rapidly growing disease, with more than six million people affected worldwide in 2016 (GBD, 2019). Although, this number was already estimated at 9.4 million by 2020 (Maserejian, 2022). It is the fastest growing disease in prevalence, disability and mortality among several neurological disorders. Subsequently, the global burden of PD, defined as the number of healthy life years lost, has more than doubled from 1990 to 2016 (GBD, 2018).

PD causes various motor problems such as rigidity, akinesia and tremor. In addition, non-motor symptoms such as depression, apathy, cognitive impairment and visual problems may occur (Antal et al., 1998). Although the classic motor symptoms of PD have been extensively researched, less research has been done on non-motor symptoms of the disease, even though these may have a negative impact on quality of life (Chaudhuri et al., 2009).

Visual problems are one of the underrecognized non-motor symptoms in clinical practice, resulting in delayed diagnoses and further worsening of visual problems (Egger et al., 2017). As a result of these visual problems, people with PD may have difficulty with everyday activities, such as reading (Hunt et al, 1995), walking (Azulay et al., 1999) and driving (Amick et al, 2007). This, in turn, can cause people with PD to become more socially withdrawn, which has a negative impact on quality of life (Santos-García & de la Fuente-Fernández, 2013). Thereby, people with PD who have visual problems appear to fall more often than people with PD without visual problems (Wood et al., 2002). Thus, especially for people with PD, it is important to recognize visual problems early on. Sufficient visual guidance of movements can compensate for their movement problems, and reduce the risk of falls and injuries (Azulay et al., 1999).

Research on visual problems tends to examine primarily what can be measured by

objective methods (Blumer & Walker, 1975). Although it is important to take objective measures to detect visual problems, it is not clear whether they fully reflect the subjective visual problems experienced by people with PD in daily life (Margolis et al., 2002). Previous research suggests that subjective visual assessments may provide additional insight into the person's visual functioning, compared to objective measurements alone (Margolis et al., 2002). Thus, subjective complaints and objective measurements do not seem comparable on a one-to-one basis. Therefore, it is possible for people to suffer from bothersome complaints without having an objectified impairment. To obtain valid and comprehensive information about functioning and impact of visual problems on the patient's life, it is important to ask about visual complaints in clinical practice. This provides the opportunity to initiate treatments based on what is important to that person, which contributes to an improved quality of life. In addition, the effectiveness of an intervention can be evaluated based on the decrease in subjective complaints.

A systematic review by van der Lijn and colleagues (2022) investigated self-reported visual complaints in people with PD. This review found visual complaints to be more often present in people with PD than healthy controls. The most common complaints in PD were blurred vision, watery eyes, light-related complaints (reduced night vision and light/dark adaptation), ocular fatigue, and activity-related complaints such as difficulty reading or driving. Less often, altered color vision and visual field deficits were found. However, only structured questionnaires were used in these studies, which means that only predetermined visual complaints could be recognized. Asking for spontaneous visual complaints (SvC) may provide additional insight into subjective visual complaints in people with PD.

The recently developed Screening of Visual Complaints questionnaire (SVCq) for people with neurodegenerative disorders appears to be a promising tool for measuring subjective visual complaints, including SvC (Huizinga et al., 2020). The questionnaire starts

with an open question about SvC, which is followed by nineteen structured items. The structured items of the SVCq appear to cover 81% of the SvC in a community sample (Huizinga et al., 2020). However, it is unclear whether this also applies to the clinical populations of people with PD.

Since SvC in people with PD have not been examined before, the first aim of this study is to investigate the SvC reported by people with PD, compared to controls. People with PD are expected to report more SvC than controls, as self-reported visual complaints are more prevalent in people with PD than healthy controls (Van der Lijn et al., 2022). In addition, the most commonly reported SvC in people with PD are expected to be largely similar to the most commonly reported visual complaints from the review by Van der Lijn et al. (2022), namely blurred vision, watery eyes, light-related complaints, ocular fatigue, and activity-related complaints. Although, it may be that people with PD, like people with acquired brain injury (Bulens et al., 1989), have more difficulty describing specific complaints than nonspecific complaints, which makes it plausible that in people with PD primarily general complaints such as blurred vision emerge among SvC, but not specific complaints such as light-related. Thereby, it will be determined to what extent the reported SvC correspond to the items of the SVCq in both groups, as previous research only examined this in a community sample. This study reinvestigates the degree of coverage in the control group, since the control group in the current study was slightly different from that of Huizinga et al. (2020), due to the age-matching of the controls to the PD group. In the control group, the coverage rate is expected to be close to 81%, as this was also found in the study by Huizinga et al. (2020). For the PD group, coverage is expected to be higher than the control group, as the SVCq was developed for people with neurodegenerative disorders.

In addition, to provide information on possible risk factors for SvC it will be examined whether the reporting of SvC in people with PD is related to demographic and disease

characteristics. Previous research has shown that self-reported visual complaints in people with PD do not seem to be related to demographic data such as age, sex and education level, but that reporting visual complaints does seem to be related to disease characteristics such as disease duration and disease severity (Van der Lijn et al., 2022). Therefore, in the present study, it is expected that reporting of SvC is not related to demographics, but is related to disease characteristics, whereby people who report SvC are expected to have a longer disease duration and higher disease severity. The review by Van der Lijn et al. (2022) did not find an unequivocal conclusion on the relationship between medication use and the reporting of visual complaints. This is because no clear relationship was found between self-reported complaints and a higher Levodopa Equivalent Daily Dose (LEDD) (e.g. Erro et al., 2003; Zhang et al., 2015; Picillo et al., 2014), whereas more visual complaints were reported by patients when medication wears off (Witjas et al., 2002; Schindlbeck et al., 2017; McDowell et al., 1997). Moreover, an association was found between LEDD and the total SVCq score (Van der Lijn et al., submitted), so it is expected that there will also be an association between LEDD and SvC in the current study.

Since people with multiple sclerosis were found to have difficulty expressing SvC when not specifically asked about them (Hoff et al., 2019), and people with acquired brain injury seem to have difficulty describing their visual complaints (Bulens et al., 1989), it will be investigated whether this is also the case in people with PD. More knowledge about this contributes to improved screening for visual complaints. This study therefore examines the difference in frequency between SvC and complaints reported on structured items on the SVCq in people with PD. It is expected that people with PD will report a visual complaint on the SVCq items more often than spontaneously, because of possible difficulties in expressing complaints.

In addition, to determine whether people who report a particular SvC also report this

complaint on the structured items of the SVCq, the sensitivity will be established in people with PD. A high sensitivity is expected, because when people are able to report a visual complaint spontaneously, it is expected that they will also report this complaint on the SVCq. Thereby, the reversed specificity will be determined to examine the extent to which people with PD who do not report a particular SvC, do report this complaint on the SVCq items. Since it seems more difficult for people with acquired brain injury to describe specific visual complaints, rather than more general visual complaints such as blurred vision (Bulens et al., 1989), this might also be the case in people with PD. Therefore a higher reversed specificity is expected for more specific than nonspecific visual complaints in people with PD. Further understanding and better recognition of subjective visual complaints in people with PD will contribute to appropriate referral and care. In addition, greater understanding of what SvC people with PD report and the ability of people with PD to express SvC will contribute to improved screening for visual complaints, allowing people to receive timely treatment and prevent further deterioration.

Method

Participants

Datasets of two Dutch-speaking samples were used in this research. The first dataset consisted of 586 individuals with PD who visited the outpatient clinic “Parkinson Expertise Center in Groningen”.

The second dataset consisted of 583 controls, without severe ophthalmic, neurologic and psychiatric conditions. This group was matched to the PD group according to age. More information on the matching procedure can be viewed in the article by Van der Lijn et al. (submitted).

Material

This study used the SVCq (Huizinga et al., 2020), which is a questionnaire on self-

reported visual complaints in people with neurodegenerative disorders. It is indicated that when people wear glasses or lenses, they should answer the question as if they were wearing them. The first question asks participants if they experienced visual complaints in everyday life. They are asked to choose the answer that is most applicable, based on the past few weeks (0 = never/hardly, 1 = sometimes, 2 = often/always). When people answered the first question with “sometimes” or “often/always”, they were asked to write down the complaints they experience, the so called “spontaneous visual complaints” or SvC. The second part consists of 19 structured items regarding several visual complaints, using the same 3-point scale as the first question. The SVCq ends with a question about the degree of limitation in daily life related to their vision, which could be rated on a scale of 0 (no limitation) to 10 (severe limitation). A good internal consistency ($\alpha = 0.85$) and test-retest reliability ($ICC = 0.82$) of the SVCq was found in healthy individuals (Huizinga et al., 2020). The Dutch and English versions of the SVCq are presented in Appendix A and B.

Procedure

A cross-sectional design was used for this study. Two existing datasets, provided by the University of Groningen and Royal Dutch Visio in Haren, were utilized. Individuals in the PD group were asked to fill out the SVCq on paper or through the online program Qualtrics (Qualtrics, Provo, UT), during a regular appointment with the neurologist. As the data in the PD group were collected during standard care, the METC of the UMCG decided that no approval was needed by the committee, meaning that only written informed consent was given by the participants for the use of their data for scientific research.

Controls were recruited via “Panel Inzicht”, a company where people get a fee for filling out questionnaires. They completed the online version of the SVCq via Qualtrics. More detailed information on the data collection can be viewed in the article by Huizinga et al. (2020). Data collection in the control group was approved by the Ethical Committee

Psychology of the University of Groningen. Participants were informed about the study prior to study inclusion, and gave written informed consent to use their data for scientific research.

Statistical analysis

Handling missing, incorrect or unclear data

A total of 142 SvC were excluded. SvC were excluded when it was not vision-related (n PD = 3, n controls = 6) or when the complaint could not be clearly interpreted (n PD = 9, n controls = 6). Furthermore, many people indicated that they needed glasses (n PD = 34, n controls = 40). However, at the beginning of the questionnaire it was mentioned that when people wear glasses, they should answer the questions as if they were wearing them, so these SvC were also excluded. Lastly, SvC were excluded when an ophthalmic condition was reported instead of a complaint (n PD = 17, n controls = 20).

Furthermore, there was missing data from people who reported experiencing visual complaints, but did not report any SvC (n; PD = 14, n; controls = 2).

For the 19 structured items of the SVCq, there was no missing data in the control group. In the PD group, data of 5 (0.9%) participants were excluded because more than 25% of the questions were not completed. This left 27 (0.2%) missing items, which were excluded in the analyses. Furthermore, five answers were excluded in the analyses because both a 0 “never/rarely” and a 1 “sometimes” were filled in. For the analyses that distinguished between “sometimes” and “often/always”, responses who checked both answer options were excluded in the analyses (n = 6). These missing or incorrect values were randomly distributed over the 19 SVCq items.

Reported SvC by people with PD and controls

The SvC of the PD group and controls were categorized according to 19 structured items of the SVCq. Complaints that did not fall under any of the 19 structured items of the SVCq were given a new category. A new category was added when a complaint was mentioned at

least twice. Complaints that occurred only once were added to the "other visual complaint" category. A frequency analysis was used to examine the prevalence of these complaints in both groups and to determine what percentage of the SvC cover the 19 items of the SVCq. To compare the frequency of SvC between people with PD and controls on each category, a chi-square test of independence was conducted using a 2 x 2 table for each category. A Bonferroni-Holm correction (Holm, 1979) was applied, by multiplying the p-value by the number of tests (Jafari & Ansari-Pour, 2019). The effect sizes were determined by calculating Cramer's V (small: 0.1-0.3, medium: 0.3-0.5 and large: > 0.5, df = 1 (Kim, 2017)).

SvC and demographics and disease characteristics

The group of people with PD who reported at least one SvC was compared with the group of people with PD who reported no SvC on demographics and disease characteristics. The Shapiro-Wilk test was used to test the assumption of normality. Since normality was violated for all variables, five Mann-Whitney U tests were used to measure the difference between people with PD reporting vs. not reporting SvC on the means of age, education level (De Vent et al., 2018), disease duration in years, disease severity (Hoehn and Yahr staging; Hoehn & Yahr, 1967) and medication use (LEDD; Tomlinson et al., 2010). Effect sizes were determined by calculating Cohen's d (small: 0.2-0.5, medium: 0.5-0.8 and large: > 0.8 (Cohen, 1992)). A chi-square test was performed to measure the association between reporting or not reporting SvC and sex. The effect size was established by calculating Cramer's V.

Difference between SvC and complaints reported on the SVCq

The frequency of the SvC reported on a given category in the PD group was compared to the frequency reported on the structured items of the SVCq of that category. The presence of a complaint on the structured items of the SVCq was noted when someone indicated "sometimes" or "often/always". A chi-square test of independence was used, with a 2 x 2 table for each item of the SVCq. In addition, the frequency of reported SvC was compared with the

frequency “often/always” on each category of the SVCq using a chi-square test. Again a Bonferroni correction was performed, by multiplying the p-value by the number of tests (Jafari & Ansari-Pour, 2019). Effect sizes were determined by calculating Cramer’s V.

Sensitivity and reversed specificity

The sensitivity of each SVCq item was determined for the PD group by dividing the number of participants who both reported a certain SvC on the first question and also reported the same complaint on the structured items, by the total number of participants who reported a SvC on this category, and multiplying it by 100. Thereby, the reversed specificity of each SVCq item was determined in the PD group by dividing the number of participants who did not report a certain SvC on the first question, but did report this complaint on the structured items, by the total number of participants who did not report this SvC on the first question, and multiplying it by 100. For sensitivity and reversed specificity, a complaint was considered present if “sometimes” or “often/always” was entered. For reversed specificity, an additional analysis was done where a complaint was considered present when only "often/always" was entered.

All statistical analyses were done using SPSS version 26 (IBM, 2019) and Microsoft Excel. The results were tested against a 0.05 significance level.

Results

Participants

Data of 581 people with PD and 583 age-matched controls were included in the analyses. Demographics and disease characteristics of both groups are presented in Table 1.

Table 1

Demographics and disease characteristics of people with PD and controls

	PD	Controls
N	581	583
Sex (n, % male)	354 (60.9%)	369 (63.3%)
Age y (M ± SD, range)	69.25 ± 9.012 (28-89)	69.17 ± 8.987 (26-89)
Education ^a (n,%)		
Low	100 (17.2%)	132 (22.6%)

Intermediate	211 (36.3%)	146 (25.0%)
High	265 (45.6%)	303 (52.0%)
Unknown	5 (0.9%)	2 (0.3%)
Disease duration y (M ± SD)	7.96 ± 6.59	
H&Y stage ^b (n,%)		
1	125 (21.5%)	
2	218 (37.5%)	
3	101 (17.4%)	
≥4	49 (8.4%)	
Unknown	88 (15.2%)	
LEDD ^c mg (M ± SD)	907.75 ± 592.01	
Unknown (n,%)	5 (0.9%)	
Visited an ophthalmologist ^d (n,%)	253 (43.5%)	243 (41.7%)
Unknown	6 (1.0%)	
Comorbidities (n,%)		
Ophthalmological ^e	203 (34.9%)	127 (21.8%)
Unknown	27 (4.7%)	49 (8.4%)
Neurological ^f	51 (8.8%)	
Psychiatric ^g	13 (2.2%)	

Note. PD = Parkinson's Disease; M = mean; SD = Standard deviation; LEDD = Levodopa equivalent daily dose; mg = milligram.

^a Categorization based on the International Standard Classification of Education (ISCED) (de Vent et al., 2018)

^b H&Y = Hoehn and Yahr staging for severity of PD (Hoehn & Yahr, 1967)

^c LEDD was calculated according to the protocol of Tomlinson et al. (2010)

^d People who self-reported having ever visited an ophthalmologist

^e Five most common ophthalmological conditions, cataract (n = 151), glaucoma (n = 28), macular degeneration (n = 23), strabismus/squint (n = 17), corneal abnormality (including pterygium) (n = 13)

^f Cerebrovascular accident (n = 16), transient ischemic attack (n = 15), epilepsy (n = 10), basilar skull fracture/traumatic injury (n = 6), thalamotomy (n = 4), encephalopathy (n = 2), brain tumor (n = 2), neuroborreliosis (n = 1), cavernoma (n = 1), and pituitary tumor resection (n = 1)

^g Schizophrenia/psychosis (n = 13)

Reported SvC by people with PD and controls

The frequencies of SvC reported on the first item of the SVCq are presented for the PD group and controls in Table 2. Unclear vision and trouble reading were most frequently reported in both groups. After that, double vision and needing more light were mentioned most often in the PD group, and difficulty with distance vision and poor/reduced vision in the control group. On the categories color vision and light-dark adjustment both groups reported no SvC.

In the PD group, 299 (51,5%) participants reported at least one SvC. In the control group, 164 (28,1%) participants reported at least one SvC. A total of 544 SvC were reported in the PD group, and 262 in the control group. The Dutch wording of all SvC are presented per category in Appendix C. In the PD group, 407 (75%) SvC fell within the categories of the SVCq, 137 (25%) were added to a new category. In the control group, 164 (63%) SvC fell within the categories of the SVCq and 96 (37%) were added to one of the new categories. A total of 14 new categories were added, making a total of 33 categories.

The chi-square test results examining the difference in frequencies between the PD group and control on each category of complaints are shown in Table 2. People with PD reported more visual complaints than controls on 27 of 33 categories. A significant difference between groups was found for the categories unclear vision, trouble focusing, double vision, needing more light, and trouble reading. Effect sizes were negligible to small. Controls reported more complaints than people with PD on the categories dry eyes, difficulty with near vision, more complaints in the morning and tearing of the eyes. Differences did not reach significance and effect sizes were negligible.

Table 2

Frequency of reported SvC and chi-square test statistics on the difference between people with PD and controls by category

SvC	PD		Controls		χ^2	<i>p</i>	Cramer's V
	N	%	N	%			
SVCq categories							
Unclear vision	112	19.3%	51	8.7%	26.79	<.001**	0.15
Trouble focusing	20	3.4%	4	0.7%	10.95	.029*	0.10
Double vision	65	11.2%	10	1.7%	43.31	<.001**	0.19
Depth perception	10	1.7%	2	0.3%	5.42	.618	0.07
Shaky, jerky, shifting images	4	0.7%	0	0.0%	4.03	>.999	0.06
Visual field loss	8	1.4%	0	0.0%	8.08	.139	0.08
Color vision	0	0.0%	0	0.0%	n/a	n/a	n/a
Reduced contrast	6	1.0%	1	0.2%	3.61	>.999	0.06
Blinded by bright light	7	1.2%	4	0.7%	0.84	>.999	0.03
Needing more light	35	6.0%	13	2.2%	10.60	.035*	0.10
Light/dark adjustment	0	0.0%	0	0.0%	n/a	n/a	n/a
Seeing things that others do not	17	2.9%	12	2.1%	0.90	>.999	0.03

Distorted images	2	0.3%	1	0.2%	0.34	>.999	0.02
Painful eyes	11	1.9%	7	1.2%	0.92	>.999	0.03
Dry eyes	2	0.3%	6	1.0%	2.00	>.999	0.04
Needing more time	1	0.2%	0	0.0%	1.00	>.999	0.03
Traffic participation	18	3.1%	5	0.9%	7.54	.187	0.08
Looking for something	2	0.3%	0	0.0%	2.01	>.999	0.04
Trouble reading	87	15.0%	48	8.2%	12.90	.010*	0.11
New categories							
Poor vision/ reduced vision	23	4.0%	17	2.9%	0.95	>.999	0.03
Difficulty with distant vision	19	3.3%	18	3.1%	0.03	>.999	0.01
Difficulty with near vision	2	0.3%	9	1.5%	4.47	>.999	0.06
Vision varies during the day	6	1.0%	0	0.0%	6.05	.431	0.07
More complaints in the morning	2	0.3%	4	0.7%	0.66	>.999	0.02
More complaints in the evening/at night	7	1.2%	5	0.9%	0.34	>.999	0.02
Difficulty watching a display/TV	22	3.8%	12	2.1%	3.07	>.999	0.05
Tiredness of the eyes	22	3.8%	10	1.7%	4.67	>.999	0.06
Tearing of the eyes	10	1.7%	14	2.4%	0.67	>.999	0.02
Eyelids close unwillingly	5	0.9%	0	0.0%	5.04	.768	0.07
Itchy eyes	2	0.3%	0	0.0%	2.01	>.999	0.04
Squeezing the eyes	2	0.3%	1	0.2%	0.34	>.999	0.02
Difficulty seeing details/small things	3	0.5%	2	0.3%	0.20	>.999	0.01
Other visual complaint	12	2.1%	4	0.7%	4.08	>.999	0.06

Note. A Bonferroni correction was applied, by multiplying all p-values by the number of tests ($n = 31$). This Bonferroni correction caused several p values to exceed one, which is indicated in the table by >.999. n/a = not available, because both PD group and controls did not report a SvC on this category; SvC = spontaneous visual complaints; PD = Parkinson's Disease; SVCq = Screening of Visual Complaints questionnaire.

* $p < .05$, ** $p < .01$

SvC and demographics and disease characteristics

The Mann-Whitney U test results examining the difference on demographics and disease characteristics between people with PD with and without SvC are shown in Table 3. Age and education level did not significantly differ between these groups, resulting in negligible effect sizes. The differences on the variables disease duration, disease severity and medication use were significant, with small effect sizes. These results suggest that people with PD with SvC have a longer disease duration, a higher disease severity and use a higher dose of medication than people with PD without SvC.

The results of the chi-square test showed that sex significantly differed between the

groups (227 women; n complaint = 132, n no complaint = 95 and 354 men; n complaint = 167, n no complaint = 187; $\chi^2(1) = 6.669$, $p < .05$), with a small effect size (Cramer's $V = 0.107$). This suggest that people with PD with SvC are more likely to be women than people with PD without SvC.

Table 3

Mann-Whitney U statistics on the difference between people with PD with and without SvC

	PD with SvC	PD without SvC				
	M ± SD	M ± SD	U	z	p	d
Age y	69.24 ± 9.08	69.26 ± 8.75	42139.00	-.010	.992	-0.00
Education	2.32 ± 0.75	2.25 ± 0.73	38703.00	-1.474	.141	0.10
Disease duration y	9.07 ± 7.04	6.78 ± 5.87	33645.50	-4.219	<.001**	0.35
H&Y stage ^a	2.30 ± 1.07	2.07 ± 0.94	26816.00	-2.374	.018*	0.23
LEDD mg ^b	1010.73 ± 638.11	796.50 ± 516.30	32118.50	-4.295	<.001**	0.37

Note. PD = Parkinson's Disease; SvC = spontaneous visual complaints; M = mean; SD = Standard deviation; H&Y = Hoehn and Yahr staging; LEDD = Levodopa equivalent daily dose; mg = milligram.

^a H&Y = Hoehn and Yahr staging for severity of PD (Hoehn & Yahr, 1967)

^b LEDD was calculated according to the protocol of Tomlinson et al. (2010)

* $p < .05$, ** $p < .01$

Difference between SvC and complaints reported on the SVCq

The frequencies of SvC and complaints reported on the structured items of the SVCq in the PD group are presented in Table 4. A total of 407 SvC were reported belonging to the categories of the SVCq. On the structured items of the SVCq a total of 3702 complaints were reported when "sometimes" and "often/always" were taken together, and a total of 1174 reported complaints on the SVCq were found when considering only those reported as "often/always". A total of 257 (44%) people with PD reported at least one SvC, whereas 527 (91%) individuals reported at least one complaint ("sometimes" or "often/always") on the SVCq items. A total of 304 (52%) people with PD answered at least one item of the SVCq with "often/always". The complaints most frequently reported on the structured items of the SVCq were unclear vision, trouble focusing, trouble reading, reduced contrast, blinded by bright light, and needing more light.

The chi-square test results examining the difference between the frequencies of the SvC and complaints reported as “sometimes” and “often/always” or “often/always” on the structured items of the SVCq in the PD group are shown in Table 4. All 19 categories showed significant results while including both “sometimes” and “often/always”. The effect sizes varied from small to large. The largest effect sizes were found on the categories trouble focusing, reduced contrast, and needing more time. When including just “often/always”, the categories unclear vision, double vision, shaky, jerky, shifting images, visual field loss, painful eyes and trouble reading did not reach significance, with effect sizes being negligible. The differences for the remaining thirteen categories were significant, with small effect sizes. In case of significant results, people with PD reported the complaint more often on the SVCq items than spontaneously.

Table 4

Frequency of SvC and complaints reported on the SVCq in the PD group and chi-square test statistics on the difference between these frequencies

Complaint	SvC		SVCq (sometimes and often/always)		SVCq (often/always)		SvC vs. SVCq (sometimes and often/always)			SvC vs. SVCq (often/always)		
	N	%	N	%	N	%	χ^2	<i>p</i>	Cramer's V	χ^2	<i>p</i>	Cramer's V
Unclear vision	112	19.3%	357	61.4%	126	21.8%	214.601	<.001**	0.43	1.098	>.999	0.03
Trouble focusing	20	3.5%	300	51.8%	99	17.1%	339.669	<.001**	0.54	58.7447	<.001**	0.23
Double vision	65	11.2%	175	30.1%	63	10.8%	63.5403	<.001**	0.23	0.035	>.999	0.02
Depth perception	10	1.7%	206	35.6%	59	10.2%	219.373	<.001**	0.44	37.1778	<.001**	0.18
Shaky, jerky, shifting images	4	0.7%	85	14.6%	12	2.1%	79.8337	<.001**	0.26	4.05585	.836	0.06
Visual field loss	8	1.4%	78	13.4%	20	3.4%	61.5306	<.001**	0.23	5.29116	.406	0.07
Color vision	0	0.0%	43	7.4%	13	2.2%	44.731	<.001**	0.20	13.1699	<.005**	0.11
Reduced contrast	6	1.0%	289	49.9%	93	16.1%	365.388	<.001**	0.56	84.0889	<.001**	0.27
Blinded by bright light	7	1.2%	278	48.1%	97	16.8%	343.582	<.001**	0.54	86.0755	<.001**	0.27
Needing more light	35	6.1%	265	45.9%	96	16.7%	240.141	<.001**	0.46	32.6292	<.001**	0.17
Light/dark adjustment	0	0.0%	200	34.4%	51	8.8%	241.58	<.001**	0.46	53.3411	<.001**	0.21
Seeing things that others do not	17	2.9%	190	32.8%	46	7.9%	176.32	<.001**	0.39	14.2218	<.001**	0.11
Distorted images	2	0.3%	85	14.7%	25	4.3%	86.238	<.001**	0.27	20.2236	<.001**	0.13
Painful eyes	11	1.9%	105	18.1%	13	2.2%	84.997	<.001**	0.27	0.177303	>.999	0.01
Dry eyes	2	0.3%	215	37.1%	69	11.9%	258.09	<.001**	0.47	67.594	<.001**	0.24
Needing more time	1	0.2%	244	42.1%	68	11.7%	306.011	<.001**	0.51	69.4186	<.001**	0.25
Traffic participation	18	3.1%	182	31.5%	64	11.1%	163.93	<.001**	0.38	28.1148	<.001**	0.16
Looking for something	2	0.3%	110	19.0%	35	6.1%	115.904	<.001**	0.32	30.58	<.001**	0.16
Trouble reading	87	15.0%	295	50.9%	125	21.6%	169.329	<.001**	0.38	8.41321	0.071	0.09

Note. A Bonferroni correction was applied, by multiplying all p-values by the number of tests (n = 19) nineteen. PD = Parkinson's Disease; SvC = spontaneous visual complaints; SVCq = Screening of Visual Complaints questionnaire.

* p <.05, **p <.01

Sensitivity and reversed specificity

Sensitivity and reversed specificity of each individual and the total SVCq are presented in Table 5. Sensitivity ranged from 63% to 100%, with the sensitivity of color vision and light/dark adjustment not being calculated, because no SvC were reported on these categories. The lowest sensitivity was found for visual field loss, meaning that 63% of those who spontaneously reported this complaint also reported it on the structured items of the SVCq. The categories with the highest sensitivity were double vision, depth perception, shaky, jerky, shifting images, reduced contrast, blinded by bright light, distorted images, dry eyes, needing more time and looking for something, which all reached a sensitivity of 100%. This means that all people who reported this complaint spontaneously also reported this complaint on the structured items of the SVCq. In addition, a sensitivity of 90% or higher was found for the categories unclear vision, trouble focusing and traffic participation. The overall sensitivity of the SVCq was 90%, which means that 90% of the SvC in the PD group were also reported on the structured items of the SVCq.

The reversed specificity including both “sometimes” and “often/always” ranged from 7% to 54%. The lowest reversed specificity was found for color vision, meaning that 7% of those who did not spontaneously report this complaint, did report it on the structured items of the SVCq. The highest reversed specificity was found for unclear vision, which means that 54% of people who did not spontaneously report this complaint, did report this complaint on the structured items of the SVCq. The overall reversed specificity of the SVCq (“sometimes” and “often/always”) was 31%, indicating that 31% of people with PD who did not spontaneously report a particular complaint, did report that complaint on the structured items of the SVCq.

While including just “often/always” the reversed specificity ranged from 2% to 16%. The lowest reversed specificity was found for shaky, jerky, shifting images, color vision, and

painful eyes, meaning that 2% of those who did not spontaneously report this complaint, did report it on the structured items of the SVCq. The highest reversed specificity was found for trouble focussing, blinded by bright light and trouble reading, which means that 16% of people who did not spontaneously report this complaint did report this complaint on the structured items of the SVCq. The overall reversed specificity of the SVCq (“often/always”) was 9%, indicating that 9% of people with PD who did not spontaneously report a particular complaint, did report that complaint on the structured items of the SVCq.

Table 5

Sensitivity and reversed specificity of the SVCq items and total SVCq in the PD group

Complaint	Sensitivity		Reversed specificity			
	Sometimes and often/always	Often/always	Sometimes and often/always	Often/always	Often/always	Often/always
	n	%	n	%	n	%
Unclear vision	104/112	93%	253/469	54%	72/468	15%
Trouble focusing	18/20	90%	281/559	50%	92/559	16%
Double vision	65/65	100%	110/516	21%	22/516	4%
Depth perception	10/10	100%	196/569	34%	51/569	9%
Shaky, jerky, shifting images	4/4	100%	81/577	14%	9/577	2%
Visual field loss	5/8	63%	73/573	13%	18/572	3%
Color vision	n/a	n/a	43/580	7%	13/580	2%
Reduced contrast	6/6	100%	283/573	49%	88/572	15%
Blinded by bright light	7/7	100%	271/571	47%	90/571	16%
Needing more light	26/35	74%	239/542	44%	82/541	15%
Light/dark adjustment	n/a	n/a	200/581	34%	51/581	9%
Seeing things that others do not	12/17	71%	178/563	32%	42/563	7%
Distorted images	2/2	100%	83/575	14%	23/575	4%
Painful eyes	9/11	82%	96/568	17%	10/568	2%
Dry eyes	2/2	100%	213/577	37%	68/577	12%
Needing more time	1/1	100%	243/579	42%	67/578	12%
Traffic participation	17/18	94%	165/559	30%	56/559	10%
Looking for something	2/2	100%	108/576	19%	33/576	6%
Trouble reading	77/87	89%	218/493	44%	81/493	16%
Total	367/407	90%	3334/10600	31%	968/10595	9%

Note. n/a = not available, because there were no people reporting a SvC on this category; PD = Parkinson’s Disease.

Discussion

Since visual problems can cause various problems in people's everyday functioning, it is important to recognise these problems in clinical practice in order to prevent further

deterioration of visual problems. By examining the SvC reported by people with PD, they can be better screened for visual problems, allowing for appropriate referral and care. Therefore, the first aim of this study was to investigate what SvC people with PD report, compared to age-matched controls. In addition, it was examined whether the reporting of SvC within the PD group was related to demographic and disease characteristics. Furthermore, the difference in frequency between SvC and complaints reported on structured items on the SVCq was determined in the PD group. Lastly, this study examined the sensitivity and reversed specificity of the SVCq items.

Reported SvC by people with PD and controls

The most frequently reported SvC in people with PD were unclear vision, trouble reading, double vision and needing more light. The hypothesis that the most common SvC are similar to the most common self-reported complaints from the review by Van der Lijn et al. (2020) is partially supported. Frequently reported SvC of unclear vision and trouble reading are consistent with previous research about self-reported visual complaints in people with PD, where a higher prevalence was found in people with PD than controls (Van der Lijn et al., 2022). However, fewer SvC were reported in the categories tearing of the eyes, light/dark adjustment and tiredness of the eyes, while these complaints were frequently reported in previous studies (Borm et al., 2020; Seichepine et al., 2011; Marques et al., 2020; Repka et al., 1996). This may be explained by the fact that in previous studies these complaints were asked about using predesigned items, whereas in this study the visual complaints were asked about spontaneously. This may reflect the difficulty that people with PD have in describing these specific visual complaints if they are not specifically asked about them, as is the case for people with multiple sclerosis (Hoff et al., 2019). In addition, people with PD may have more difficulty describing more specific than general complaints (Bulens et al., 1989), which could explain why a complaint such as light/dark adjustment was not spontaneously reported.

Regarding SvC in general, people with PD reported SvC more often than controls. This is in line with previous research, wherein several studies showed a higher prevalence of self-reported visual complaints in people with PD than controls (Biousse et al., 2004; Almer et al., 2012; Schmidt et al, 2008; Hamedani & Willis, 2020; Urwyler et al, 2014; Brandt et al., 2018). In addition, the study by Van der Lijn et al. (2020) concluded that all complaints from the structured items of the SVCq were more frequent or more severe in people with PD than controls. This is consistent with the pre-established hypothesis, showing that SvC are, like the visual complaints reported on the structured items of the SVCq, more frequently reported by people with PD compared to age-matched controls.

When looking at specific SvC, people with PD reported complaints significantly more often than controls on the categories unclear vision, trouble focusing, double vision, needing more light, and trouble reading. These categories are equivalent to the most commonly reported SvC in people with PD, and all belong to the categories of the SVCq items. They are also largely consistent with the results of the systematic review on self-reported visual complaints in people with PD by Van der Lijn et al. (2022), where a higher prevalence of visual complaints in the categories unclear vision, double vision and trouble reading was found in people with PD compared to controls. Less research seems to be done on complaints of trouble focusing and needing more light. However, two studies found that problems can arise in low-light situations (e.g. when driving at night) (Amick et al., 2007; Archibald et al., 2009). In addition, the prevalence of these complaints was significant higher among people with PD than controls on the structured SVCq items (Van der Lijn et al., submitted), and thus corresponds to the higher prevalence of SvC in people with PD compared to controls.

Although the frequency of SvC in the PD group was higher than controls on 22 of the 28 remaining categories, no significant differences were found in these. This is interesting since several studies do find a significantly higher prevalence in people with PD on complaints as

increased sensitivity to light, light/dark adjustment, painful, dry or watery eyes, changes in contrast sensitivity, visual field impairment and driving difficulties (e.g. Borm et al., 2020; Urwyler et al., 2014; Tamer et al., 2005; Almer et al., 2012; McDowell & Harris, 1997). In addition, the prevalence was significantly higher on all of these complaints in people with PD than controls on the structured item of the SVCq (Van der Lijn et al., submitted). This can be explained by the fact that in the current study fewer SvC, than when asked for in a structured way, were reported on these categories, making the difference between groups less pronounced. The fact that these specific complaints were reported less spontaneously was expected and may be due to the difficulty of describing specific complaints on the basis of an open question.

In the PD group, 75% of the SvC fell within the items of the SVCq, while in the control group 63% of the SvC fell within the SVCq items. The coverage in the control group is interesting and contrary to expectations, as previous research found that 81% of the SvC fell within the SVCq items in a community sample (Huizinga et al., 2020). The difference with the sample from the study by Huizinga et al. (2020) is the sample size which was almost three times larger ($n = 1461$ vs. $n = 581$ in our study). However, the sample of the current study was extracted from this sample to age-matched to the PD group, resulting in a higher mean age compared to the sample of Huizinga et al. (2020) (69.2 vs. 54.9 years). However, no logical explanation can be found for the difference in coverage based on the differences in sample size and mean age. A more plausible explanation could be that the categorisation of complaints was done somewhat differently in the article by Huizinga et al. (2020). It seems that the current study created a new category for certain SvC, while Huizinga et al. (2020) placed these complaints under an existing SVCq category. For example, complaints such as poor vision/reduced vision could be included under the existing category of unclear vision, because people who report poor vision may mean that they do not have sharp vision.

However, this is difficult to interpret, as poor vision can also mean something other than unclear vision. Therefore it was decided to consider it as a separate category in the current study, whereas this was not done in the article by Huizinga et al. (2020). Coverage in the PD group is higher than in the control group, confirming the preconceived hypothesis and suggesting that the visual complaints experienced by people with PD largely correspond to the items on the SVCq. Therefore, the SVCq seems to be a good instrument to assess visual complaints in people with PD in clinical practice, which was expected as the questionnaire was designed for this target group. However, the open-ended question does reveal additional visual complaints that would have been missed when only structured items were asked. Most frequent were complaints regarding poor/reduced vision, difficulty watching a display/TV, tiredness of the eyes, and difficulty with distant vision. This demonstrates the importance of asking an open question in order to assess the visual complaints experienced by people with PD. An option would be to include the most frequently mentioned visual complaints that fell outside the items of the SVCq in the questionnaire. However, certain complaints that are less frequently reported spontaneously will still be missed, so it is not a substitute for the open question. In addition, it is not desirable to have a long questionnaire, since the SVCq is meant to be a short screening. Nevertheless, the most common SvC in people with PD and the SvC in which a clear difference between PD and controls emerged are covered by the SVCq. Thus, despite the fact that some complaints are missed, the SVCq seems to cover the most clinically relevant items.

SvC and demographics and disease characteristics

This study showed that people with PD with SvC were more likely to be women, have a longer disease duration, a higher disease severity and use a higher dose of medication than people with PD without SvC.

The sex difference is not consistent with the pre-established hypothesis and contradicts

existing literature, with the majority of study's finding no difference between sexes in self-reported visual complaints (e.g. Durcan et al., 2019; Borm et al., 2020; Tomic et al., 2017), and one study reporting that men were more likely to report visual complaints (Davidsdottir et al., 2005). So far, no logical explanation has been found for the difference that was found in the present study, although it should be taken into account that it may have been a coincidence finding, which is supported by the small effect size found.

The reporting of SvC by people with PD with longer disease duration and higher disease severity is consistent with the pre-established hypothesis and previous research (Van der Lijn et al., 2022), suggesting that visual complaints increase as PD progresses. It can be hypothesised that this relationship is still underestimated in the current study, as increasing symptoms (such as motor (Kang et al., 2005) and cognitive decline (Muslimovic et al., 2007)) may cause people to write down fewer SvC, because cognitive decline may be associated with lack of awareness and failure to report problems to the clinician (Koerts et al., 2012).

This study found, as expected, a relationship between the reporting of SvC and LEDD. This is in contrast to a number of studies where no relationship between LEDD and visual complaints was found (Erro et al., 2013; Zhang et al, 2015; Picillo et al., 2014; Kim et al. 2019; Verbaan et al. 2007). Although, these studies investigated the association of a specific visual complaint and LEDD (e.g. double vision and increased sensitivity to light). The studies that examined visual complaints in general in relation to LEDD, did find a relation between the reporting of visual complaints and medication dose (Brandt et al., 2018; Van der Lijn et al., submitted). It could therefore be that LEDD is associated with visual complaints in general, but not with a specific visual complaint.

No relationship was found between the reporting of SvC and mean age and education level, which was expected and in agreement with existing literature (Van der Lijn et al., 2022).

These results show that visual complaints seem to increase as PD progresses. It is therefore important to screen people repeatedly on visual complaints from the moment that PD is diagnosed in order to limit deterioration of visual function.

Difference between SvC and complaints reported on the SVCq

On all categories, people with PD were less likely to report a SvC than to report a complaint on the structured items of the SVCq (“sometimes” and “often/always”), which is consistent with the pre-established hypothesis. The difficulty in describing specific complaints that people with PD may have (Hoff et al., 2019) could be an explanation for this. The complaints most frequently reported on the SVCq items largely corresponded to those most frequently reported spontaneously, namely unclear vision, trouble focusing, trouble reading and needing more light. However, there was a large difference in frequency between the SVCq and SvC for the categories trouble focusing and needing more light. This was also the case for the categories reduced contrast and blinded by bright light. So, in particular the complaints trouble focusing, reduced contrast, blinded by bright light and needing more time seem difficult to describe without being specifically asked in people with PD. Therefore, it is important to use structured items to ask about these specific visual complaints in people with PD, as some visual complaints may be missed with an open-ended question alone.

The difference became much smaller for all categories, when SvC were compared with complaints reported on the structured items of the SVCq as “often/always” (as opposed to “sometimes” and “often/always” as described before). The difference was no longer significant for the categories unclear vision, double vision, shaky, jerky, shifting images, visual field loss, painful eyes and trouble reading. Thus, it seems that people with PD are more likely to report a SvC when they experience this complaint as more severe, especially for the abovementioned categories. This may indicate that these complaints are easier to describe for people with PD than the categories in which the difference remained significant.

Nevertheless, it is important to ask about visual complaints in a structured way, because the risk of only asking open-ended questions is that visual complaints that are more difficult to describe for people with PD are missed when not specifically asking about them.

Sensitivity and reversed specificity

The overall specificity of the SVCq was high (Lange & Lippa, 2017). This was expected and shows that most people who reported a particular SvC also reported this complaint on the structured items of the SVCq. However, when looking at the reversed specificity, it emerges that almost one third of the people who do not spontaneously report a certain complaint still report this complaint on the structured items of the SVCq (“sometimes” and “often/always”). This was expected and could be explained by the difficulty they might have in describing specific visual complaints and demonstrates the importance of asking about specific visual complaints in a structured way, because otherwise these complaints would be missed. The overall reversed specificity decreased to less than ten percent when only the SVCq answer option “often/always” was taken into account. This shows that people with PD are more likely to report a visual complaint spontaneously if they perceive the complaint as more severe.

Looking at specific categories, it is notable that categories of double vision, depth perception, shaky, jerky, shifting images, reduced contrast, blinded by bright light, distorted images, dry eyes, needing more time and looking for something reached a sensitivity of 100%. Thus, if people report this complaint spontaneously, this complaint is also recognised and reported on the items of the SVCq. However, a specificity of less than 80% was found for the categories visual field loss, needing more light and seeing things that others do not. Therefore, when people report a SvC on one of these categories, they do not always report this complaint on the SVCq items. This may be because people do not recognise the complaint they report spontaneously, on the items of the SVCq. For example, if it is reported

that someone sees spots before the eyes, this SvC is placed under the category seeing things that others do not. However, when reading the SVCq item “Do you see things that others do not see?”, people might interpret this as something else than seeing spots. It could therefore be considered to include seeing spots as a separate category, as this was also done in the study by Huizinga and colleagues (2020). Another example is, when someone reported not being able to see well in the dark, this SvC is added to the category of needing more light. However, people with PD may not report this complaint on the SVCq items (do you need more light than before?). Finally, someone reported having tunnel vision, which is categorised as visual field loss. Although, this complaint was not reported on the SVCq item (do you feel that you are missing parts of the field of vision?). This underlines the importance of asking about SvC as people sometimes experience something other than what is covered by the SVCq item.

Regarding the reversed specificity (“sometimes” and “often/always”) a percentage of over 40% was found for the categories unclear vision, trouble focusing, reduced contrast and blinded by bright light, needing more light, needing more time and trouble reading. These complaints are thus often mentioned on the SVCq items, while they are not spontaneously reported. Therefore, it is important to ask about these visual complaints in a structured way, because otherwise these visual complaints may be missed. A reversed specificity of less than 20% was found for the categories shaky, jerky, shifting images, visual field loss, color vision, distorted images, painful eyes and looking for something. This could mean that only a small percentage of people who did not report a complaint spontaneously, did report this complaint on the SVCq. However, it may also be that these complaints were generally not mentioned much, which automatically makes the reversed specificity lower. Since the categories with the lowest reversed specificity were also the categories least reported on the SVCq, the latter seems to be the case.

When looking at the reversed specificity (“often/always”), it is noticeable that all

percentages have become lower than the percentages of reversed specificity ("sometimes" and "often/always"). It could apply that if people with PD experience a complaint as severe, they are more inclined to report that complaint both spontaneously and on the SVCq. Therefore, only a small percentage of people with PD report a complaint on the SVCq items as "often/always", if this complaint was not reported spontaneously. Although this can only be stated for complaints that are frequently reported on the SVCq ("often/always") (unclear vision, trouble focusing, reduced contrast and blinded by bright light, needing more light and trouble reading), because the reversed specificity is automatically lower for complaints that are less frequently reported on the SVCq ("often/always") (shaky, jerky, shifting images, visual field loss, color vision, distorted images and painful eyes). Interestingly, the percentages of the categories unclear vision and double vision decreased strongly, as these categories were one of the most frequently reported complaints on the SVCq ("often/always") and were often reported spontaneously. These complaints therefore seem easier to report spontaneously, especially when complaints are severe, which was expected since general complaints are often easier to report than specific ones (Bulens et al., 1989).

The hypothesis that the reversed specificity will be higher for predominantly specific complaints than for more general complaints is not supported. This may be explained by the fact that the reversed specificity depends on the number of complaints reported on the SVCq, with the percentages being automatically lower for complaints that are less frequently reported, resulting in several percentages of specific complaints being lower than general complaints.

Strengths, limitations and recommendations for future research

This study has a number of strengths. First, a large sample size was used, which increases the generalizability of the conclusions to the population. In addition, the SVCq appears to be a good measure because it seems to capture the most common SvC in people

with PD and the SvC with the greatest differences from controls. However, the fact that visual complaints are more frequently reported on the SVCq than spontaneously suggests that the frequency of SvC that fall outside the SVCq categories is underestimated. The exact prevalence of these complaints is therefore not known, making it important to investigate this in future research.

In addition, a number of limitations must be taken into account in this study. Firstly, all SvC were subjectively categorised. This may have led to certain assumptions being made about the meaning of a SvC when this might not correspond to what someone meant by it, also called the observer bias effect (Mahtani et al., 2018). An attempt was made to prevent this as much as possible by having a second person assess the visual complaint in cases of doubt.

Another limitation is that 70% of the people with PD in this study were in the first or second stage of PD according to the staging of Hoehn and Yahr (1967), making the results less applicable and generalizable to people with higher disease severity as in stages three, four and five. Future research could focus on the SvC in these stages of PD, as more complaints are reported as the disease progresses.

This study applied a Bonferroni correction to the number of tests done for the comparison between people with PD and controls on the reporting of SvC and for the comparison between SvC and complaints on the SVCq. This was done as a precaution, to reduce the chance of a coincidence finding (type I error). Since many tests were performed ($n = 31$ and $n = 19$), a large correction had to be made, resulting in multiple findings not reaching significance. While this decision is supported, the Bonferroni correction may have been too strict with this large number of tests, increasing the chance that differences were not found (type II error).

Finally, this study only considered a subjective measuring instrument. Although

literature shows that subjective measuring instruments can give additional information about someone's visual functioning compared to objective measuring instruments alone (Margolis et al., 2002), it is unclear whether the subjective visual complaints experienced by people with PD correspond to visual problems measured with objective measuring instruments. Future research could focus on the relationship between visual complaints and visual impairments, in order to find out the best way to recognize visual problems at an early stage in clinical practice, and to provide the most appropriate care.

Conclusion

This study shows that the most frequently reported SvC in people with PD are unclear vision, trouble reading, double vision and needing more light. Certain complaints appear easier to report spontaneously than others, e.g., difficulty reading seems easier to report than light/dark adjustment. In particular, these seem to be more general complaints relative to specific ones. In addition, people with PD appear more likely to report a complaint spontaneously if they perceive this complaint as severe. Since people with PD report more SvC than controls and the visual complaints increase as PD progresses, it is important to repeatedly screen people for visual complaints. This study contributes to a better understanding of the best way to screen for these visual complaints. Since, people with PD are more likely to report visual complaints on structured items than spontaneously, it is important to ask about visual complaints in a structured way, because otherwise complaints as trouble focusing, reduced contrast, blinded by bright light and needing more time will be missed. However, it is also important to ask for SvC, as these can reveal additional complaints, such as poor/reduced vision, difficulty watching a display/TV, tiredness of the eyes and difficulty with distant vision, that will be missed by structured items alone. The SVCq seems to be a good screening tool because it asks both open-ended and structured questions.

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Appendix A



SCREENING VISUELE KLACHTEN (SVK)

Datum:

Naam:

Geslacht:

Geboortedatum:

Wat is uw hoogst afgeronde opleiding?

Dit is een vragenlijst met uitspraken over problemen die met uw zicht te maken hebben. Als u een bril of contactlenzen heeft, ga er dan bij de beantwoording van de vragen vanuit dat u deze draagt.

Elke vraag heeft meerdere antwoordmogelijkheden. Kies het antwoord dat het meest op u van toepassing is. Het gaat daarbij steeds om de afgelopen weken.

Als u niet zeker weet welk antwoord u moet kiezen, geef dan het best passende antwoord.

Kruis bij alle volgende vragen s.v.p. 1 antwoord aan. Er zijn in totaal 3 pagina's.

	Ja	Nee
Bent u bekend bij een oogarts?	<input type="checkbox"/>	<input type="checkbox"/>
Indien 'Ja': Bij welke oogarts (of welk ziekenhuis) bent u bekend?		
Voor welke oogheekundige aandoening(en) bent u bekend bij de oogarts?		

	Nee/ nauwelijks	Soms	Vaak/ altijd
1 Ervaart u in het dagelijks leven problemen met uw zicht?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Indien 'Soms' of 'Vaak/altijd': Kunt u aangeven welke problemen of klachten u heeft met uw zicht?			
a.			
b.			
c.			
d.			

		Nee/ nauwelijks	Soms	Vaak/ altijd
2	Heeft u de indruk dat u minder scherp bent gaan zien?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Heeft u moeite met scherpstellen of duurt het langer voordat u een scherp beeld heeft?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Heeft u last van dubbelzien of dubbelbeelden?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Heeft u moeite met dieptezien of afstanden inschatten?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Heeft u last van trillende, schokkerige of bewegende beelden?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Heeft u het idee dat u delen mist in het gezichtsveld?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Ervaart u kleuren anders dan vroeger?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	Heeft u moeite met het zien bij verminderd contrast (bijv. wanneer letters niet zijn afgedrukt op een witte, maar op een grijze achtergrond)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	Wordt u, meer dan vroeger, verblind door fel licht?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	Heeft u de indruk dat alles donkerder lijkt of heeft u meer behoefte aan licht dan vroeger?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	Heeft u moeite met het wennen aan licht of donker?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	Ziet u wel eens dingen die anderen niet zien (denk bijv. aan flitsen, patronen, voorwerpen of dieren)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	Heeft u de indruk dat u voorwerpen of gezichten anders waarneemt, bijvoorbeeld vervormd of met nabeelden?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	Heeft u pijn aan uw ogen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Nee/ nauwelijks	Soms	Vaak/ altijd
16 Heeft u last van droge ogen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17 Heeft u het idee dat u meer tijd nodig hebt om dingen te zien?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18 Heeft u moeite met zien of waarnemen bij deelname aan het verkeer (lopen, fietsen en autorijden)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19 Heeft u, <u>vanwege uw zicht</u> , moeite met het zoeken en vinden van dingen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20 Heeft u, <u>vanwege uw zicht</u> , moeite met lezen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Geef een cijfer van 0 tot 10 (omcirkel het juiste antwoord)			

21 In hoeverre wordt u in het dagelijks leven gehinderd door bovenstaande klachten met betrekking tot het zien?

0 1 2 3 4 5 6 7 8 9 10

0 = geen hinder

10 = zeer ernstige hinder

	Ja	Nee
Stelt u advies, onderzoek en/of revalidatie voor de hierboven genoemde klachten op prijs?	<input type="checkbox"/>	<input type="checkbox"/>

Wilt u controleren of u alle vragen heeft beantwoord?
Bij elke vraag dient 1 antwoord aangekruist te zijn.

Dank u wel. Dit is het einde van de vragenlijst.

Appendix B



SCREENING VISUAL COMPLAINTS (SVC)

DISCLAIMER: The following questionnaire is a first English translation of the original Dutch questionnaire. This English version has not been validated yet and therefore does not guarantee similar validity and reliability as the Dutch version.

Date:

Name:

Sex:

Date of birth:

What is your highest level of education?

The following list of questions concerns problems that you may have with your eyesight. If you wear glasses or contact lenses, please assume that you are wearing these when you answer the questions.

Each question has several possible answers. Please choose the answer that is most appropriate to your situation as it has been over the past weeks.

If you are not certain, please choose the answer that best reflects your situation.

Please choose 1 answer for each of the following questions. The questionnaire consists of 3 pages.

		Yes	No	
	Did you ever visit an ophthalmologist?	<input type="checkbox"/>	<input type="checkbox"/>	
	If 'Yes': Which ophthalmologist did you visit or at which hospital did you visit an ophthalmologist?	<input type="text"/>		
	For which ophthalmologic condition did you visit an ophthalmologist?	<input type="text"/>		
		No/ Hardly ever	Sometimes	Often/ Always
1	Do you experience problems with your eyesight in daily life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	If 'Sometimes' or 'Often/Always': please describe your problems or complaints regarding your eyesight	a. <input type="text"/>		
		b. <input type="text"/>		

		No/ Hardly ever	Sometimes	Often/ Always
	c.			
	d.			
2	Do you have the impression that your vision has become less clear?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Do you have trouble focusing or does it take longer before things are in focus?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Do you have double vision or see double images?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Do you have problems with depth perception or estimating distances?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Do you see shaky, jerky or shifting images?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Do you have the impression that you cannot see part(s) of the visual field?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Do you experience colour differently than before?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	Do you have trouble seeing things at reduced contrast (e.g. letters that have not been printed on a white but on a grey background)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	Are you more easily blinded by bright light than before?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	Do you have the impression that everything looks darker or that you need more light than before?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	Do you have difficulty adjusting to light or dark environments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13	Do you see things that others do not see (e.g. flashes of light, patterns, objects or animals)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	Do you have the impression that you perceive objects or faces differently, for example, distorted or with afterimages?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	Are your eyes painful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	Are you bothered by dry eyes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17	Do you feel that you need more time to see things?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18	Do you have vision problems when you participate in traffic (walking, cycling or driving)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19	Do you have trouble looking for objects and finding objects <u>due to your eyesight</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20	Do you have trouble reading <u>due to your eyesight</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please indicate your answer on a scale of 0 to 10 <i>(please circle the relevant answer)</i>				
21	To what extent do you experience limitations in daily life due to the above mentioned problems with eyesight?	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 10		
	<i>0 = no limitations</i>			
	<i>10 = very severe limitations</i>			
		Yes	No	
	Would you appreciate advice, assessment and/or rehabilitation for the abovementioned complaints?	<input type="checkbox"/>	<input type="checkbox"/>	

Please check whether you answered all questions.
One answer must be ticked for each question.

Thank you very much. This is the end of the questionnaire.

Appendix C

Dutch wording of all SvC by category

Unclear vision/onduidelijk zicht

<u>Parkinson's disease</u>	<u>Controls</u>
<p>Wazig zien; Wazig en onduidelijk; Wazig zien; rechteroog zomaar wazig een tijdje; zie minder scherp; Wazig; Scherp zien; Niet scherp ; Wazig zicht; vooral 's avonds/bij vermoeidheid wazig zicht; Wazig zien; Wazig zien; Wazig zien; Wazig zien; onvoldoende scherp zien, bijv. bij lezen; als ik moe ben zowel dichtbij als veraf wazig; Wazig zien; Soms wazig zien; Wazig zien; Scherp zien; wazig zien; Wazig zien; Vaag zien; s ochtends is er een waas voor mijn ogen; wazig zien; Iets 'troebel' zicht; Wazig zien; Minder scherp; Wazig; fluctuerende scherpheid van scherp tot wazig; Onscherp zien; Wazig zien; Wazig; wazig gezichtsveld; wat vochtige ogen 's ochtends, daardoor wazig; Wazig; Rechteroog dat is minder scherp; rechteroog verandert de scherpheid; Soms wazig zien; wazig/dubbelzien sinds + 2 jaar; Wazig zien; Wazig zien; soms wazig zien (als pupil</p>	<p>Af en toe wazig zicht; Wazig zien; Wazig; Wazig zien; Wazig; Soms wazig zien; Ik zie niet altijd alles scherp; Onduidelijk zien; Wazig zicht; Af en toe iets wazig; Troebelingen in mijn linker oog; Troebel zien/wazig zien; Wazig zien; Wazigheid; Linker oog iets minder scherp; Wazig zicht; Soms troebel; Af en toe on scherp; Wazig zien; Vaag zien; Wasig; Zie alles minder scherp dan zou moeten; 's morgens wazig en onscherp zicht; Wazig zien. Na druppels weer goed; 's morgens slecht zicht niet scherp genoeg; Rechteroog soms wazig; Wazig; Momenteel het zien door een waas; Onverklaarbaar soms wazig; Soms wazig; Wazig zien; Wazig, vooral bij dichtbij kijken; Soms niet duidelijk zien; Onscherp zien; Onscherp zien; vermoeidheid zodat ik niet scherp kan zien; Zie wazig; Niet altijd even scherp zien; Wazig sliertjes; Wazig zien; Wazig; Soms wazig zien; Vooral in de</p>

<p>verwijd is); Niet scherp meer zien; Nevelig zicht; Niet scherp zien; Wazig zien; Onscherp zicht; Onscherp zien; wazig zien, vooral 's morgens na het opstaan; Moeite met scherp zien; Soms niet scherp; Wazig zien; Wazig kijken soms; Geen helder zicht, wazig, mistig; Wazig; Het word soms wazig geen scherpe zicht meer; Wazig zien; Niet scherp zien; Wazig zien; Wazig; Bij vermoeidheid wordt het beeld wat waziger; Soms wat wazig; Wazig zien; Wazig zien; Soms wazig zien; Minder scherp zien; Wazig; Onscherp zien; Wazig zien; soms wazig zien, wisselende ervaring daarbij; Wazig zicht; Minder scherp zien; Soms wazig; Onscherp zien bij reparatiewerkzaamheden, kleine details; Wazig zien; Wazig zien, onduidelijk zien; Minder scherp zien; Niet scherp zien; wazig zicht; Niet scherp zien; Wazig zien; Lichte waas voor het linkeroog; Scherp zien; Wazig zien; Scherppte; Soms wazig dan gebruik ik artelie oogdruppels; Soms wazig; Onscherp zien; Wazig zien; Onscherp zien; wazig zien of delen wazig; Soms .</p>	<p>avond wazig zien; Onduidelijk zicht; Wat wazig zien; Wazig; Bij dragen multifocale lenzen zie ik in de schemering minder scherp; Soms zie ik niet scherp; Soms heb ik weer een waas voor mijn ogen; Soms zie ik heel wazig, vooral als ik iets langer lees; Om goed scherp te zien moet ik veel mijn; hoofd bewegen</p>
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<p>Onscherp; Wazig; Wazig zien; Wazig zien; Wazig zen; Wazig zien, vooral als ik moet; Niet scherp kunnen zien; Wazig; Wazig zien; Mistig; Elke dag wazig zien; Wazig beeld (soms); Niet scherp; door moeheid wat onscherp zien; moet ik turen; Niet scherp zien; Niet meer scherp zien; Wazig; Troebel zichtsveld; Wazig zien</p>	
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Trouble focusing/scherpstellen

<u>Parkinson's disease</u>	<u>Controls</u>
<p>Na lang lezen niet makkelijk scherp stellen in de verte; Soms vaag zicht na kijken dichtbij, het instellen van de ogen duurt langer; Duurt lang voordat ik scherp zicht heb; Ik kan tijdens lezen niet focussen maar moet mijn bril afzetten en de tekst heel dichtbij; Niet kunnen focussen; Het scherpstellen op verschillende afstanden; Focus problemen; Focussen, scherpstellen; Overgang van veraf naar dichtbij; Focussen met variofocus bril; Focus klachten; Slecht focussen bij dichtbij; Omschakeling veraf en dichtbij; Bij vermoeidheid wordt het beeld wat waziger. Meer moeite om te focussen;</p>	<p>Focus; Ogen niet scherp stellen in de ochtend/ogen niet scherp stellen bij kunstlicht; Scherpstellen door de mousses; Veraf en dichtbij die overgang duurt wat langer</p>

<p>bij wisselen bril duurt het ongeveer 45 seconden voordat ik goed zie; Moet goed focussen; Niet scherp kunnen stellen; Scherpstellen; Scherpstellen; Kan slecht focussen</p>	
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Double vision/dubbelzicht

<u>Parkinson's disease</u>	<u>Controls</u>
<p>Dubbelzien; Dubbelzien; Dubbel zien; Dubbelzien; Dubbelzien; Dubbel zicht; Hallucinaties (= dubbel zien); Dubbel zien; Beeld is dubbel, dwz overlapt elkaar; Dubbel zien; Dubbelzien; Dubbel zicht; Dubbelzien; Zie met linkeroog dubbel; Dubbelzien; Dubbelzien; Dubbelzien; Dubbelzien; Dubbel zien; Dubbelzien; Dubbelzien; Dubbelzien > blijft; Dubbelzien; Dubbelzien; Dubbelzien sinds + 2 jaar; Dubbelzien; Dubbelzien, altijd aanwezig middenin het oog; i.v.m. dubbelzien geen auto; Dubbelbeelden, niet te corrigeren; Dubbelzien; Soms dubbelzien bij lezen aan tafel; Dubbel zien; Dubbel; Dubbelzien; Dubbel zien; Soms dubbel zien; Dubbel zien; Dubbel zien en tranende ogen</p>	<p>Ik zie vaak alles dubbel; Na staar operatie dubbel zien; Dubbel beeld van autolichten; Dubbel zien; Soms dubbel zien; Verticaal dubbel zien; Soms dubbelzien; Dubbel zicht; Dubbel; Zie dubbel als ik in de verte kijk</p>

<p>bij lezen; Dubbelzien; Dubbelzien;</p> <p>Dubbelzien; Dubbel zien; Dubbele beelden;</p> <p>Dubbel zien; Dubbelzien; Soms dubbel zien;</p> <p>Soms dubbel zien; Dubbelzien; Dubbel zien,</p> <p>voornamelijk bij het kijken op tv/iPad;</p> <p>Dubbel zien; Dubbel zien; Soms dubbel</p> <p>zien; Dubbelzien met linker oog; Dubbel</p> <p>zien; Bij vermoeidheid dubbel zien;</p> <p>Dubbelzien; Dubbel zien; Dubbelzien;</p> <p>Dubbelzien; Dubbelzien; Dubbelzien;</p> <p>Dubbelbeeld (vaak); Dubbelzien;</p> <p>Dubbelzien; Dubbelzien</p>	
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Depth perception/dieptezien

<u>Parkinson's disease</u>	<u>Controls</u>
<p>Bij het lezen kan ik moeilijk de afstand</p> <p>bepalen; Gebrek aan contrast en diepte;</p> <p>Diepte inschatten; Hoogte op/afstap</p> <p>inschatten; Moeite met inschatten bochten</p> <p>en afstanden; Dingen pakken gaat moeilijk</p> <p>(diepte zien lastig); Hoogten, diepten;</p> <p>Moeilijk afstand meten; Dieptezien; Diepte</p> <p>niet meer zo goed</p>	<p>Zie geen diepte; Diepte zien</p>

Shaky, jerky, shifting images/trillende, schokkerige, verschuivende beelden

<u>Parkinson's disease</u>	<u>Controls</u>
Wiebelend beeld door menièrre; Lichte trillingen bij bepaald lijnenspel; Bewegend beeld; Een niet stilstaand beeld, net of het steeds trilt	-

Visual field loss/gezichtsveldverlies

<u>Parkinson's disease</u>	<u>Controls</u>
Mis soms gedurende + 20 minuten deel zicht letters niet allemaal zichtbaar; Tunnelvisie; Het verkleind, net als of ik in trechter kijk; Zicht beperking door overhangende oogleden; Dingen mis grijpen; Gezichtsveld beperking rechts; Het eten op mijn bord laat ik soms een gedeelte van liggen; Gezichtsveld wordt minder	-

Color vision/kleurenzien

<u>Parkinson's Disease</u>	<u>Controls</u>
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Reduced contrast/verminderd contrast

<u>Parkinson's disease</u>	<u>Controls</u>
Gebrek aan contrast en diepte; Contrast;	Meer licht/contrast nodig bij lezen

Minder onderscheidings vermogen; Soms zie ik gedeeltelijk niets door missen van contrast; Slecht zicht bij weinig contrast (lezen); Minder contrast zien, met name in donker	
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Blinded by bright light/verblind door fel licht

<u>Parkinson's disease</u>	<u>Controls</u>
Overgevoelig voor fel licht; Last van (schel) licht; Kan niet tegen fel zonlicht; Bij veel tegen of vel licht gaan mijn ogen dicht, heb ik moeite ze open te houden; Verschil met verlichting dat aan staat (tegenlicht); Last van felle zon; Scherpe licht van auto's 's avonds	Kan niet tegen felle zon aan 1 oog; Minder goed tegen licht kunnen; Tranende ogen door te fel licht, te lang lezen of computer; Met licht, dus meekleurende glazen

Needing more light/meer licht nodig

<u>Parkinson's disease</u>	<u>Controls</u>
Autorijden als het donker is; 's Avonds autorijden; Nachtblind (kan 's avonds niet meer autorijden); Vooral 's avonds/bij vermoeidheid wazig zicht; Nachtblind + in donker wazig zien; Lezen 's avonds; In donker autorijden; Autorijden bij donker; Bij te weinig licht geen goed zicht; Slecht	Meer licht/contrast nodig bij lezen; Zien bij schemeren; 's Nachts zie ik heel slecht; In donker slecht zien; Minder goed kunnen lezen bij donkeren omgeving en bij kleine letters; Zie minder in donker; Nachtblind matig; 's Avonds slechter zien; Bij dragen multifocale lenzen zie ik in de schemering

<p>zien in donker; Veel licht nodig; Lezen gaat moeilijk, vooral 's avonds; Minder goed kunnen lezen bij minder licht; 's Avonds minder scherp; Moeite met zicht in avond en nacht bij autorijden; Problemen met rijden in donker, minder zicht; Nachtzicht; Lezen gaat niet zonder lamp; Slecht zien bij nacht; In donker zien; In donker buiten onzeker; In het donker autorijden; In het donker slecht zien; Veel licht nodig bij het lezen; Meer licht nodig bij lezen etc.; Lezen bij schaars licht is soms lastig; Als het donker is; Nachtblind; Last nachtblindheid; In het donker zie ik niets; Slecht zicht in het donker; Minder contrast zien, met name in donker; 's Avonds moeite met bv. Puzzelen; Meer licht nodig; Op de dag de lamp aan in huis</p>	<p>minder scherp; Zie slecht in het donker (altijd gehad, zeker sinds 50 jaar); Nachtblind; Slecht zien in het donker; Bij donker rijden</p>
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Light/dark adjustment/licht/donker adaptatie

<u>Parkinson's disease</u>	<u>Controls</u>
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Seeing things that others do not/dingen zien die anderen niet zien

<u>Parkinson's disease</u>	<u>Controls</u>

<p>Hallucinaties (=dubbel zien); Soort spinnetjes voor de ogen; Vlekken; Zwarte “draadjes” zien; Soms: lichtflitsen; Zwarte vlekken bij lage bloeddruk; Gele vlekken als schaduw; Bij het 's nachts wakker worden zie ik gedurende + 2 minuten 'zwarte bollen'. Dit verdwijnt daarna weer; Lichtflitsen; Zie soms iets passeren wat er helemaal niet is; Vlokjes voor het oog; Soms is het net of er water om mij heen staat; Vlokken in de ogen rechts het ergst; Sterretjes/lichtpuntjes zien/lichtinval; “Kladden”, vlekken op het oog; Hallucinaties, maakt veraf zien onzeker; Hallucineren</p>	<p>Vlekken; Soms zwarte vlekken; Vlekjes voor de ogen; Vlekjes; Vlekken; Vlokjes, kikker vis sliertjes; “Zwarte plekjes” zien; Wazig sliertjes; Friemeltjes voor mijn ogen; Door staaroperatie in beide ogen achterste glasvochtloslating; Flutertjes drijven af en toe langs; Na de staaroperatie heb ik last van zwevende deeltjes</p>
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Distorted images/vervormde beelden

<u>Parkinson's disease</u>	<u>Controls</u>
Vervorming van beeld; Vervorming	Bril vertekend bij het klussen, kan niet recht zagen

Painful eyes/pijnlijke ogen

<u>Parkinson's disease</u>	<u>Controls</u>
Linkeroog soms stekend (overgehouden aan beschadiging); Branderige ogen (weinig knipperen); Zand in de ogen; Alsof er zand	Soms branderig gevoel; Brandende ogen ; Steken, pijnlijk gevoel; Pijn; Prikkende; Branderige, tranende ogen; Brandende ogen

in ogen zit; Branderige ogen; Branderige ogen; Prikkeling in de ogen; Brandende ogen; Pijn in rechteroog rechts; Branderig; Brandende en tranende ogen	
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Dry eyes/droge ogen

<u>Parkinson's disease</u>	<u>Controls</u>
Droge ogen; Droge ogen	Droog rechter oog, waardoor het zicht minder wordt; 's Morgens droge ogen; Vaak moeten knipperen door de droogte van de ogen; Droge ogen; Te droge ogen, zodat ik mijn lenzen niet kan dragen; Droge ogen

Needing more time/meer tijd nodig

<u>Parkinson's disease</u>	<u>Controls</u>
Ik loop achter met het zien	-

Traffic participation/verkeersdeelname

<u>Parkinson's disease</u>	<u>Controls</u>
Autorijden als het donker is; 's Avonds autorijden; Nachtblindheid (kan 's avonds niet meer autorijden); In donker autorijden; Wegbelijning loopt in elkaar over bij autorijden; Autorijden; Autorijden bij donker; Als ik in de auto zit zie ik slecht;	Kan wegbewijzing moeilijk lezen op afstand; Dubbelbeeld van autolichten; 's Nachts minder zicht bij autorijden (snelweg), borden lezen; Moeilijk autorijden 's avonds; Bij donker rijden

<p>Lezen vd borden; Scherp stellen, tijdens autorijden; Auto rijden; Moeite met zicht in avond en nacht bij autorijden; Problemen met rijden in het donker, minder zicht; Angstig, qua mobiliteit, gaan zitten, lopen etc.; In het donker autorijden; Hulp nodig bij vervoer; Bij autorijden soms “verspringende” beelden, i.p.v. vloeiend; Auto</p>	
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Looking for something/zoeken van iets

<u>Parkinson's disease</u>	<u>Controls</u>
Geen overzicht, waardoor dingen maar blijven liggen; Dingen vaak niet vinden	-

Trouble reading/moeite met lezen

<u>Parkinson's disease</u>	<u>Controls</u>
<p>Lezen; Lezen; Met lezen; Erg veel moeite met lezen; 's Morgens slecht lezen van de krant; Lezen gaat niet; Moeite met lezen; Met lezen (ouderdom); Bij het lezen; Met lezen (ouderdom); Bij het lezen kan ik moeilijk de afstand bepalen; Onvoldoende scherp zien, bijv. bij lezen; Lezen is vermoeiend; Lezen 's avonds; Lezen;</p>	<p>Lezen; Lezen is soms moeilijk; Lezen wordt minder; Leesproblemen; Lezen; Problemen met lezen ook met bril; Moeite met lezen; Lezen; Ik kan de kleine letters niet meer lezen; Meer licht/contrast nodig bij lezen; Lezen; Met dichtbij, lezen e.d.; Lezen enz.; Lezen; Af en toe problemen met lezen; Oogen (om te leezen); Lezen; Met lezen;</p>

<p>Overgang leesgedeelte; Lezen; Slaat wel eens een regel of woord over; Dichtbij lezen; Leesproblemen; Tekst bij lezen schuift in elkaar; Mis soms gedurende + 20 minuten deel zicht letters niet allemaal zichtbaar; Lezen; Ik kan tijdens lezen niet focussen maar moet mijn bril afzetten en de tekst heel dichtbij; Lezen; Lezen; Lezen van boeken; Lezen; Verschoven letters/woorden; Lezen; Lezen ook heel moeilijk; Lezen; Lezen; Moeilijk lezen; Leesafstand; Ogen vallen dicht bij lezen; Kan niet duidelijk meer lezen; Slecht lezen; Sommige gedrukte teksten; Verspringen van tekst; Wazig en dubbel bij lang lezen; Plotseling letters niet meer kunnen lezen; Krant lezen; Lastiger lezen; Krant lezen, vlak bij; Lezen; Vermoeide ogen bij het lezen; Lezen gaat moeilijk, vooral 's avonds; De letters niet goed kunnen zien; Kleine letters in tijdschriften; Veel lezen vermoeid; Verandering van ogen waardoor het lezen moeizamer wordt; Lezen; Beperkt in alles, ook ontspanning (lezen, puzzelen etc.); Lezen; Lezen, krant lezen; Slecht zicht bij</p>	<p>Lezen; Lezen; Het niet goed kunnen lezen van een tekst; Na verloop van tijd niet goed meer kunnen lezen; Lezen; Minder goed kunnen lezen bij donkere omgeving en bij kleine letters; Lezen; Lezen gaat moeilijker; Lezen; Lezen wordt lastiger; Lezen; Minder zicht in de verte en met lezen; Lezen lastig; Lezen; Moeite met kleine letters; Slecht lezen; Niet goed kunnen lezen; Heb moeite met lezen; Moeilijk lezen; Slecht lezen; Dichtbij lezen; Lezen; In de verte lezen; Lezen; Tranende ogen door fel licht, lang lezen of computer; Ik kan soms de letters niet lezen; Slecht zien bij lezen; Soms zie ik heel wazig, vooral als ik iets langer lees; Boek, krant; Soms bij kleine letters lezen</p>
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<p>weinig contrast (lezen); Lezen; Soms gaat het lezen moeilijk; Lezen; Met lezen; Dubbel zien en tranende ogen bij lezen; Lezen wordt moeilijker; Lezen; Leesproblemen veraf en dichtbij; Lezen; Bij het lezen; Moeite met kleine letters; Letters te klein; Soms wat minder goed kunnen lezen tekst; Moeite met lezen; Lezen; Lezen; Wazig zicht bij lang lezen; Plotseling niet meer goed kunnen lezen (wordt beter na druppelen); Hele kleine lettertjes; Vooral kleine letters zoals bijsluiters; Moeilijkheden met lezen; Leesprobleem; Met lezen; Kleine letters; Soms niet goed kunnen lezen; Met lezen later waarnemen; Lezen; Kan dus slecht lezen etc.; Kleine tekst kunnen lezen; Lezen (puzzelen)</p>	
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Poor vision/reduced vision/slecht zicht/minder zicht

<u>Parkinson's disease</u>	<u>Controls</u>
<p>Minder zicht; Minder zicht; Niet goed kunnen zien; Ik zie slecht; Slecht zien; Eén op ander moment slechter of beter; Slecht zien; Soms niet duidelijk genoeg; Slechter kunnen zien; De 1 keer beter dan de andere</p>	<p>Minder zicht; Slecht zien veraf (dus op straat); Slecht zicht; Ogen tranen veel waardoor zicht af en toe minder is; Minder gezicht vermogen; Zie steeds slechter; Droog rechter oog, waardoor het zicht</p>

<p>keer; Over het algemeen is het zicht slechter geworden; Linkeroog wordt soms plotseling slecht; Slecht tot zeer slecht zicht, 20% rechts en 60% links; Slecht zicht; Bril in niet echt in staat om mijn slechtzienheid te corrigeren; Wisselend zicht, is verschillend over de dag; 40 en 60 procent; Slecht zien; Ziet niet alles goed; 2 jaar geleden bril met multifocale glazen aan laten meten. Ik vind het zicht met deze glazen minder dan voorheen; 50% minder zicht met linkeroog; 1% gezichtsveldvermogen; Bij vermoeidheid minder zicht</p>	<p>minder wordt; Rechteroog 5%, linkeroog 12%; Minder zicht; Minder zicht in verte; Slecht zien; Minder goed zien; Slecht zien moeilijk lezen; Slecht zien; Af en toe wat slechter zicht; Links vrijwel blind (aangeboren); Slechtzienheid</p>
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Difficulty with distant vision/moeite met zicht in de verte

<u>Parkinson's disease</u>	<u>Controls</u>
<p>In de verte slecht zien; Soms slecht veraf zien; Ver zien; Afstand kijken; Voor veraf zie ik slecht; Ik lees (na staaroperatie) zonder bril. Beeld wordt vager bij omhoogkijken of bij verder weg; Veraf kijken; Moeite met scherp zien in de verte; Slecht in de verte zien; Niet goed scherp zien in de verte; Zicht in de verte; Met in de verte zien; Scherp kunnen zien op afstand is</p>	<p>Afstand; Minder scherp ver kijken; Veraf zicht; Veraf minder zicht; Minder ver zicht; Op afstand moeite; Slecht zien op afstand; Moeite met verafzien; Minder zicht in de verte en met lezen; Slecht ver zien; Veraf kijken; Veraf zien niet scherp; Verzien; Slecht verzien; In de verte lezen; Veraf legt aan het licht; Zie dubbel als ik in de verte kijk; Afstand</p>

soms lastig; Ver af wazig; Problemen met zien op afstand; Hallucinaties, maakt veraf zien onzeker; Minder scherp zien veraf; Bij verder weg kijken geen scherp beeld	
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Difficulty with near vision/moeite met dichtbij zicht

<u>Parkinson's disease</u>	<u>Controls</u>
Bril op wel ver zien maar niet dichtbij; Kort afstand geen zicht	Dichtbij zien; Van dichtbij moeite met zicht; Met dichtbij, lezen e.d.; Dichtbij kijken, lezen enz.; Slecht zicht van dichtbij; Dichtbij zicht; Dichtbij zien; Wazig, vooral bij dichtbij kijken; Dichtbij

Vision varies during the day/zicht wisselt over de dag

<u>Parkinson's disease</u>	<u>Controls</u>
Wisselend gezicht vermogen; Plotseling letters niet meer kunnen lezen; De 1 keer beter zien dan de andere keer; Linkeroog wordt het zicht soms plotseling slecht; Wisselend zicht, is verschillend over de dag; Plotseling niet goed meer kunnen lezen (wordt beter na druppelen)	-

More complaints in the morning/meer klachten in de ochtend

<u>Parkinson's disease</u>	<u>Controls</u>

<p>'s Ochtends is er een waas voor mijn ogen; Wazig zien, vooral 's morgens na het opstaan</p>	<p>'s Morgens droge ogen; 's Morgens wazig en onscherp zicht; 's Morgens slecht zicht niet scherp genoeg; Ogen niet scherp stellen in de ochtend</p>
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More complaints in the evening/at night/meer klachten in de avond/nacht

<u>Parkinson's disease</u>	<u>Controls</u>
<p>Nachtblind (kan 's avonds niet meer autorijden); Lezen 's avonds; 's Avonds tranende ogen; Bij het 's nachts wakker worden zie ik gedurende + 2 minuten 'zwarte bollen'. Dit verdwijnt daarna weer; Lezen gaat moeilijk, vooral 's avonds; 's Avonds minder scherp; 's Avonds moeite met bv. Puzzelen</p>	<p>'s Nachts zie ik heel slecht; 's Nachts minder zicht bij autorijden (snelweg); Vooral in de avond wazig zien; Nachtblind matig; 's Avonds slechter zien</p>

Difficulty watching a display/TV/moeite met het kijken naar een beeldscherm/TV

<u>Parkinson's disease</u>	<u>Controls</u>
<p>TV kijken; TV kijken; Ondertiteling TV; Lezen van beeldscherm; Bril voldoet niet bij computerwerk; Afstand tekst lezen (tv); Vaak de letter vergroten op pc reader enz.; TV kijken; Televisie kijken soms met bril dan weer zonder; Tv kijken; Ondertiteling van de TV; Tv kijken; Computer kijken,</p>	<p>Soms schittertering als ik tv kijk, na 5 min trekt het weer weg en word mijn zicht beter; Beeldschermwerk; Scherm laptop bekijken; Met de tv als de letters te klein zijn; Computer; Te lang achter beeldscherm, wazig zien; Niet goed kunnen zien/lezen op de pc; Tranende ogen door te fel licht, te</p>

<p>telefoon kijken; Voor tv kijken heb ik een bril nodig; Moeite met lezen van ondertiteling tv op 3m afstand; Dubbel zien, voornamelijk bij het kijken op tv/iPad; Ondertiteling tv (soms, bij lichte achtergrond); Ondertiteling kan ik veelal niet ontcijferen lezen; Bewegende beelden, bijvoorbeeld TV kijken; Kijken naar de tv komt soms wazig over; Van smartphone lezen; TV ondertiteling</p>	<p>lang lezen of computer; Slecht zien bij lezen, tv kijken; Computer; Moeilijk lezen tekst TV; Als ik te lang naar de tv kijk word ik moe in mijn ogen</p>
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Tiredness of the eyes/vermoeide ogen

<u>Parkinson's disease</u>	<u>Controls</u>
<p>Ogen worden moe van wisseling brillen; Met vermoeide ogen overbewegelijk, draaien; Vooral 's avonds/bij vermoeidheid wazig zicht; Als ik moe ben zowel dichtbij al veraf wazig zicht; Uiteindelijk val ik in slaap; 's Avonds als ik moe word; Ogen vallen dicht bij lezen; Vermoeide ogen; Wazig en dubbel zien bij lang lezen; Vermoeide ogen bij het lezen; Veel lezen vermoeid; Vermoeidheid; Bij vermoeidheid wordt het beeld wat waziger. Meer moeite om te focussen; Langdurig geconcentreerd</p>	<p>Moeheid; Vermoeide ogen; Vermoeide ogen; Als ik moe wordt zie ik slechter; Wanneer ik moe ben; Lezen, snel vermoeide ogen; Vermoeidheid zodat ik niet scherp kan zien; Vermoeide ogen; Soms zie ik heel wazig, vooral als ik iets lager lees; Als ik lang naar de tv kijk word ik moe in mijn ogen</p>

<p>kijken; Vermoeide ogen; Vermoeide/zware ogen; Bij vermoeidheid dubbel zien; Vermoeidheid; Wazig zien, vooral als ik moe ben; Bij vermoeidheid minder zicht; Moe op de ogen; Door de moeheid wat onscherp zien</p>	
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Tearing of the eyes/tranende ogen

<u>Parkinson's disease</u>	<u>Controls</u>
<p>Tranige ogen, wazig zien; Wat vochtige ogen 's ochtends, daarvoor wazig; Hangend onderste ooglid (links) en daardoor tranende ogen; Tranende ogen; 's Avonds tranende ogen; Tranende ogen; Ogen tranen regelmatig; Dubbelzien en tranende ogen bij lezen; Tranende ogen; Tranende ogen</p>	<p>Waterige ogen; Snel tranende ogen vooral bij koud weer; Ogen tranen veel waardoor zicht af en toe minder is; Tranende ogen; Vaak te vochtig, alsof er kou op mijn ogen is; Tranende ogen; Tranende ogen; Tranende ogen; Tranende ogen; Tranende ogen; Af en toe tranende ogen; Traanogen; Tranende ogen door te fel licht, te lang lezen of computer</p>

Eyelids close unwillingly/ogen vallen dicht

<u>Parkinson's disease</u>	<u>Controls</u>
<p>Ooglid zakt wat naar beneden; Ogen vallen dicht bij lezen; Ogen vallen soms dicht, zware oogleden; Mijn ogen gaan steeds dicht; Meerdere keren per dag vallen mij de</p>	-

ogen bijna dicht	
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Itchy eyes/jeukende ogen

<u>Parkinson's disease</u>	<u>Controls</u>
Jeukende ogen; Jeuk	-

Squeezing the eyes/knijpen met de ogen

<u>Parkinson's disease</u>	<u>Controls</u>
Knijpen met ogen; Ogen dichtknijpen	Knijpen

Difficulty seeing details/small things/moeite met het zien van details/kleine dingen

<u>Parkinson's disease</u>	<u>Controls</u>
Klein werk (met kleine schroefjes b.v.); Alle priegel klussen; Onscherp zien bij reparatiewerkzaamheden, kleine details	Kleine voorwerpen; Kleine dingetjes zien

Other visual complaints/andere visuele klachten

<u>Parkinson's disease</u>	<u>Controls</u>
Naar links kijken; Wennen aan bril, door leesgedeelte kijken; "Flipperen" van de ogen; Moet meer moeite doen om alles goed te zien; Uiteenlopende beelden; Onrustig beeld; Soms worden letters geel van kleur; Golfen; Schrijven; Sleutelen; Duizelig; Als het regent	Niemand herkennen (of laat); Vind lastig om bril of contact lenzen te gebruiken. Moet eigenlijk wel vanwege leeftijd wel; Moeilijk hierbij de juiste bril aan te schaffen; Niet goed de ogen van iemand zien