# A SURVEY OF SLEEP DISORDERS AMONG DUTCH VISUALLY IMPAIRED PERSONS

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#### **INTRODUCTION**

The majority of visually impaired persons (VIP's) suffer from excessive daytime fatigue, sleepiness and dysphoria. Both VIP's and therapists consider these complaints to be caused by compensatory effort needed to fulfill daytime activities in case of blindness or diminished sight. Alternatively, insomnia and disturbed circadian control of sleep may play a pivotal role in the causation of this syndrome. Sleeping problems among the totally blind are well known and documented <sup>1-4</sup>. Several studies show that over 50% of the blind have severe problems with the quality of their sleep and fatigue during the day. Research in New Zealand suggests a 26% prevalence of Circadian Rhythm Sleep Disorder (CRSD) among VIP's.<sup>5</sup> In 2005 the prevalence of blindness in the Netherlands is estimated to be 0,4% (75.881 people) and of visual impairment 1% (225.525 people). <sup>6</sup> The number of people with visual impairment suggests the possibility of a widespread sleeping problem. The presence of sleeping problems will be compared with results from a sample of the Dutch population.<sup>7</sup>

#### METHODS

Respondents (VIP's as well as their partners) were recruited through a national fair for VIP's. At the fair an online questionnaire was launched that was made available on a secluded website. Respondent were also invited through publications in media that were targeted at VIP's. The questionnaire included validated questions about sleepiness and sleeping disorders, and additional questions about visual disability, personal status and sleep habits. The presence of a sleep disorder was measured with the 32-item Holland Sleep Disorders Questionnaire (HSDQ)<sup>8</sup>. The HSDQ generates one global sleep disorder score and differentiates between the 6 main categories of sleep disorders as defined in the ICSD-2, i.e. insomnia, parasomnia, CRSD, hypersomnia, restless legs syndrome, and sleep-related breathing disorder. In this research we focus on the incidence of a General Sleep Disorder (GSD) and two specific sleep disorders: insomnia and CRSD. Sleepiness was measured using the 8-item Epworth Sleepiness Scale (ESS)<sup>9</sup>, and a set of 15 additional questions about demographics, ophthalmic disease quality of sleep and daytime fatigue. Daytime rhythm was measured with the questions: 'do you have a regular daily rhythm e.g. regular mealtimes, working hours and/or bedtimes' (range 1-5) and 'do you have daily activities outdoors' (range 0-7). Subjects were asked to select the category that best described their current percentage of vision (visual acuity). Response choices included: "no visual impairment, sighted," "over 30% vision," (11,7%) "15-30% vision," (18,6%) "5-15% vision," (18,6%) "1-5% vision," (24,8%) or "blind." (26,3%). Individuals identifying themselves as sighted (n=16) were described as a separate category. Respondents were also

asked to select the category that best described their ophthalmic disease. Based on the answers (n=270) an anatomical classification due to the specific location of the visual impairment was made, leading to the following 5 categories: blindness because of absent bulbus (15,2%), visual impairment due to optic nerve disease (15,2%), to retinal disease (56,3%), to other neuro-ophthalmologic disease (3,7%) and to unknown causes (9,6%). In further analyses the categorization visual acuity and location was used to determine whether these factors influence the presence of a sleeping disorder. Adults between the ages of 18 to 85 years were eligible. A total of 289 data records were completed by 273 visually impaired individuals (159 females age 52,48 ± 16,57 years, 114 males; mean age 52.11± 15.40 years) and 16 fully-sighted individuals (8 females, 8 males; mean age 48.19 ± 14.84 years). There was no statistically significant difference for age or gender between the fully-sighted and visually impaired groups.

Missing values on the HSDQ were replaced by the average score on the specific item. Continuous variables (HSDQ, ESS) were presented as mean  $\pm$  standard deviation. Categorical variables (location, vision) were expressed as percentages and their 95% confidence intervals. The presence of a General Sleep Disorder (GSD) and the incidence of Insomnia or CRSD was assessed. Next the incidence of a GSD was compared across the groups vision and location using chi-square test with Bonferroni correction or Fisher's exact test, as appropriate. Additional questions about sleep and daily activities were compared between groups using analyses of variance (ANOVA), and the Mann–Whitney U-test. Correlations were evaluated using the Pearson test. Logistic regression (method enter) was used to test the association between the presence of a sleep disorder as dependent factor and age, gender, visual acuity, location, daily activity and daily rhythm as predictors. Statistical procedures were performed using the Statistical Package for Social Sciences, (SPSS version 21.0: SPSS Inc., Chicago, IL, USA). For all tests values of p<.05 were considered to be significant.

## **RESULTS AND DISCUSSION**

A majority of the visually impaired respondents (54%) has a general sleep disorder (GSD). Gender and age did not have a statistically significant effect on GSD. In table 1 the presence of a general sleep disorder is presented per category of vision.

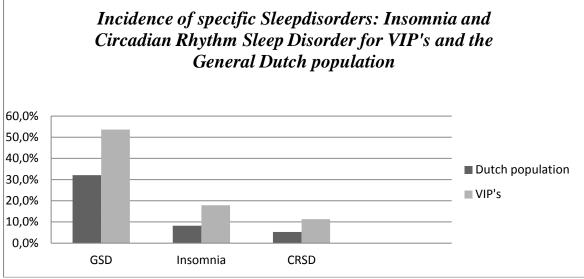
Vision	Percentage
Blind (n=71)	50,7 <sup>a</sup>
1-5 % (n=67)	46,3 <sup>a</sup>
5-15 % (n=51)	49,0 <sup>a</sup> 58,8 <sup>a, b</sup>
15-30 % (n=51)	58,8 <sup>a, b</sup>
Over 30% (n=32)	78,1 <sup>b</sup>
Fully sighted partners (n=13)	46,2

Table 1: Prevalence of General Sleep Disorder by category of visual acuity

Each subscribt letter denotes a subset of visus categories whose column proportions do not differ significantly from each other at the .05 level.

For every category of visual acuity the incidence of a GSD is significantly higher than for the general Dutch population (32,1%). The respondents with 15-30% vision and with 30% vision have a significant higher incidence of a GSD as compared to the categories with less vision. When considering insomnia and CRSD more closely, the incidence of both sleeping disorders is almost twice as high as the prevalence in the Dutch population, (Figure 1).





<Include figure 1 here>

Of the 31 respondents meeting the CRSD criteria, 24 (77%) were diagnosed with insomnia as well. In the next table information about the sleep related questions, for each category vision is presented.

Sleep related questions	Blind	1-	5-	15-	More
		5%	15%	30%	than
					30%
How many hours of night sleep do you usually get? (n=272, range 4-9)*	6.24	6.96	6.69	6.65	6.97
Do you consider your night sleep to be enough? (n=270, range 1-3)*	1.46	1.56	1.51	1.43	1.50
How do you consider the quality of your night sleep? (n=271, range 1-5)*	2.99	3.22	3.22	3.18	3.10
Do you experience fatigue or sleepiness during the day? (n=273, range 1-5)*	2.96	3.19	3.22	3.16	3.19
I am a sleeper (n=274, range 1-5)* Do you have a regular daily rhythm?	2.88	3.26	2.90	3.00	3.03
(e.g. regular mealtimes, working hours and/or bedtimes (n=273, range 1-5)*	3.89	3.96	3.78	3.73	3.56
Do you have daily activities outdoors? (n=271, range 0-7)	4.56	4.59	4.12	4.55	4.19
Sumscore Epworth Sleepiness Scale (n=248, range 0-23)*	7.64	4.59	4.09	4.50	3.56

 Table 3 : Mean score on sleep related questions compared for vision.

With regard to the vision categories there are no significant differences. However, there is a trend for hours of sleep (p<.06) and the sumscore on the ESS (p<.09). The additional questions in Table 3 marked with an asterisk (\*) differ significantly between the groups with and without a GSD. We tested the predictive value of a model for developing a GSD. Variables entered in the logistic regression as predictors were age, gender, visual acuity, location of ophthalmic disease, daily activities and daily rhythm. A (self-reported) irregular daily rhythm is the strongest independent predictor for developing a GSD. The more irregular the rhythm, the higher the odds to develop a GSD. (OR 6,91, p<.05). Nagelkerke Rsquare .09.

Vision contributes to a GSD as well, the higher the remaining percentage of vision, the more likely to develop a GSD (OR 5,31, p < .05). There seems to be a relation between a higher percentage of vision, and a more irregular daily rhythm. A possible explanation for this unexpected result might have to do with the fact that respondents with Macular Degeneration (an age related ophthalmic disease) are overrepresented in these categories. Similar results as for daily rhythm were found for daily activity. The lower the number of days with daily activity within a week, the higher the likelihood to develop a GSD (OR 4,54, p < .05). Although a large number of VIP's filled out the questionnaire, and good sleepers were invited to participate, it is possible that respondents with sleeping problems are overrepresented. This sample is not representative for ophthalmic disease. We advise a broader investigation, with visual acuity and ophthalmic disease diagnosed by an ophthalmologist instead of self report. Reactions from VIP's on the results from this research however, suggest a widespread sleeping problem.

## CONCLUSIONS

VIP's have a higher risk for a sleep disorder, in particular insomnia and Circadian Rhythm Sleep Disorder than the general Dutch population. An irregular daily rhythm is the strongest predictor for developing a GSD, followed by the degree of visual acuity and a lack of daily activities on the third place. Thus, the reported daytime fatigue seems more likely to be caused by a sleeping disorder than by the strain caused by the visual impairment. Deregulation of the sleep-wake cycle might play a crucial role. Although a person can be blind, unconscious perception of light by retinal ganglion cells, might still be possible <sup>10</sup>. If synchronization by light is missing, 'Zeitgebers' like regular mealtimes and sport times, can synchronize the circadian rhythm <sup>11</sup>. For therapy we suggest to strengthen alternative 'Zeitgebers' more often.

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