Homonymous Hemianopia: Impact on Daily Life and the Effects of Scanning Training on Mobility

dehaan, Gera Ada

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Difficulties in daily life reported by patients with homonymous visual field defects

ABSTRACT

Background: Homonymous visual field defects (HVFD) are common after postchiasmatic acquired brain injury and may have a significant impact on independent living and participation in society. Vision-related difficulties experienced in daily life are usually assessed using questionnaires. The current study 1) links the content of 3 of these questionnaires to the International Classification of Functioning, Disability and Health (ICF) and 2) provides analyses of vision-related difficulties reported by patients with HVFD and minimal comorbidities.

Methods: Fifty-four patients with homonymous hemianopia or quadrantanopia were asked about difficulties experienced in daily life because of their HVFD. This was performed during a structured interview including 3 standardized questionnaires: National Eye Institute Visual Functioning Questionnaire, Independent Mobility Questionnaire, and Cerebral Visual Disorders Questionnaire. The reported difficulties were linked to the ICF according to the ICF linking rules. Main outcome measures were presence or absence of experienced difficulties.

Results: The ICF linking procedure resulted in a classification table that can be used in future studies of vision-related difficulties. Besides well-known difficulties related to reading, orientation, and mobility, a high proportion of patients with HVFD reported problems that previously have not been documented in the literature, such as impaired light sensitivity, color vision, and perception of depth.

Conclusions: A systematic inventory of difficulties experienced in daily life by patients with HVFD was performed using the ICF. These findings have implications for future study, assessment and rehabilitation of patients with HVFD.

INTRODUCTION

It has been estimated that homonymous visual field defects (HVFD) occur in 89% of patients with acquired postchiasmatic brain damage (Zihl, 2011). The most common form of HVFD is homonymous hemianopia. Estimated percentages of homonymous hemianopia among stroke patients range from 8% to 31% (Feigenson et al., 1977; Gilhotra et al., 2002). HVFD can have far-reaching negative effects on both general and vision-related quality of life (Gall, Franke et al., 2010; Papageorgiou et al., 2007; Wagenbreth et al., 2010). HVFD has been mainly associated with difficulties in reading, orientation and mobility (Chen et al., 2009; Gassel & Williams, 1963b; Papageorgiou et al., 2007; Trobe et al., 1973; Warren, 2009; Zihl, 1995b; Zihl, 2011). De Haan et al. (De Haan, Heutink, Melis-Dankers, Tucha, & Brouwer, 2014, chapter 3) pointed out that only a small percentage of studies on HVFD have focused on the consequences of HVFD on daily activities and participation in society.

In this study, a systematic inventory was performed on the difficulties experienced in daily life by patients with HVFD. Although several studies have reported on a number of difficulties caused by HVFD, the results were not based on systematic exploration, or resulted from very small patient groups or patients with other physical impairments. In our study, patients with HVFD had minimal comorbidities and to minimize bias from previous studies or clinical experience, a predefined classification system (International Classification of Functioning, Disability and Health; ICF) was used. A better understanding of the difficulties experienced in daily life by patients with HVFD hopefully will lead to better assessment and treatment methods.
METHODS

Participants

Patients were recruited from Royal Dutch Visio and Bartiméus, the 2 largest centers for rehabilitation for blind and partially sighted people in the Netherlands. Between 2010 and 2012, 373 patients suspected of having HVFD applied for rehabilitation at these institutes. Patients were subjected to extensive and standardized ophthalmologic and neuropsychological testing. In order to be included in the study, a HVFD was required. Time since origin of the field defect had to exceed 5 months, minimizing chances for spontaneous recovery of the field defect. Patients were excluded if visual acuity was ≥ 20/40 or if they had impaired ocular motility. Further exclusion criteria were symptoms of neglect, memory problems, depression, anxiety disorder, mini-mental state examination score < 24 or disorders of visual perception including visual spatial perception, visual object recognition, visual attention, or visuoconstruction.

Fifty-four patients met inclusion criteria and consisted of 35 men and 19 women with a mean age of 56 years (range, 27-75 years). In 37 patients, the HVFD was left-sided and 17 right-sided. The field defects existed for 20 months on average (range, 5-122 months). Eleven patients had a quadrantanopia (10 left-sided and 1 right-sided), whereas the remaining 43 cases had a hemianopia. Causes of the HVFD were ischemic stroke \( (n = 39) \), hemorrhagic stroke \( (n = 6) \), traumatic brain injury \( (n = 3) \), penetrating head trauma \( (n = 1) \), tumor resection \( (n = 1) \), extirpation of arteriovenous malformation with postoperative hemorrhage \( (n = 1) \), or combined etiology \( (n = 3) \).

All patients provided written informed consent. The Medical Research Ethics Committee of the University Medical Center Groningen approved the study. The study was performed in accordance with the 2008 Declaration of Helsinki.

Procedure and materials

Patients were examined individually during a structured interview. The assessment began with an open-ended request to name the difficulties they experienced in daily life because of their HVFD. Next, the effect of the HVFD on an extensive set of different situations was assessed using 3 standardized questionnaires. The Visual Functioning Questionnaire (NEI-VFQ-25) (Mangione et al., 2001) consists of multiple choice questions concerning the influence of visual impairment on several health-related domains, including emotional well-being, social functioning, and tasks related to daily visual functioning. With the Independent Mobility Questionnaire (IMQ) (Turano, Geruschat, Stahl, & Massof, 1999), the perceived ability for independent mobility despite visual impairment is evaluated. Patients rated on 5-point scales the amount of difficulty they experience in 35 mobility situations. In the second portion of the IMQ, the respondent is asked about mobility-related behavior, such as falling, use of mobility aids, and medication usage. The first part of the Cerebral Visual Disorders (CVD) questionnaire consists of 9 questions to assess the presence or absence of vision-related problems (Kerkhoff, Schaub, & Zihl, 1990). In the second part, respondents are asked to indicate on 5-point scales how much difficulty is experienced with 12 particular activities (Tant, 2002). The CVD contains questions not only on mobility and reading but also on other vision-related problems, such as perception of depth and colors, light sensitivity, and visual hallucinations. The combination of
Difficulties in daily life reported by HVFD patients

Table 4.1. steps in the process of conversion and analysis.

<table>
<thead>
<tr>
<th>Step 1: analysis of reported difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spontaneously reported difficulties</td>
</tr>
<tr>
<td>• Linking every spontaneously reported complaint to one or more ICF codes</td>
</tr>
<tr>
<td>• Calculating per ICF code how many patients report at least one problem in this category</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Standardized questionnaires</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Linking every item to one or more ICF codes</td>
</tr>
<tr>
<td>• Converting scaled scores into dichotomous scores (absence or presence of the problem the item refers to)</td>
</tr>
<tr>
<td>• Calculating per ICF code how many patients report presence of a problem on at least one of the items in this category</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Step 2: in-depth analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standardized questionnaires</td>
</tr>
<tr>
<td>• Examining on the item level the percentages of patients reporting the presence of a problem. This was done for problems that appeared less directly related to missing half of the visual field.</td>
</tr>
</tbody>
</table>

these questionnaires enables extensive examination of a wide range of functions, activities, and participation. Since reading difficulties are common in patients with HVFD, the questionnaires were administered in oral interviews.

**Step 1: Analysis of reported difficulties**
The process of conversion and analysis are listed in Table 4.1.

**Linking the reported difficulties to the ICF**
Since the 3 questionnaires in total contained 102 questions, categorization of the items of these questionnaires, as well as the answers to the open-ended questions, was necessary for an accessible overview of the reported difficulties. Several methods for categorizing items or concepts have been used previously. Such classifications were often based on face validity or common sense and sometimes descriptions of how categories were constructed were completely missing. Although these methods can be very effective to answer certain research questions, they can easily be subject to bias.

To keep an unbiased objective approach in evaluating the reported difficulties, we applied a predefined classification system as a reference framework. The ICF (World Health Organization, 2001), as developed by the World Health Organization, has been used in numerous studies (Bruyere, Van Looy, & Peterson, 2005; Cerniauskaite et al., 2011; De Haan et al., 2014; Fayed, Cieza, & Bickenbach, 2011). In the ICF, concepts related to the health are categorized in body functions and structures, activities and participation, as well as environmental factors and personal factors. These components are further structured in domains and categories, resulting in unique codes for individual concepts.

In our study, 3 investigators working in the field of visual perception and familiar with the ICF model independently determined the concepts included in the questions and answers. Each concept was linked to the most precise ICF code according to the guidelines by Cieza et al. (2005) using the digital ICF browser (http://apps.who/int/classifications/icfbrowser). When comparisons of the 3 classifications revealed differences, an attempt was made to reach consensus. If this failed, a fourth evaluator was involved.
Difficulties in daily life reported by HVFD patients

Table 4.2. Transformation of different rating scales into dichotomous scales. The item is rated as problem present in case one of the bold options is chosen by the participant. If this is not the case then the item is rated as problem absent.

<table>
<thead>
<tr>
<th>Visual Functioning Questionnaire (NEI-VFQ-25)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 1</td>
</tr>
<tr>
<td>(1) excellent, (2) very good, (3) good, (4) fair, (5) poor</td>
</tr>
<tr>
<td>Item 2</td>
</tr>
<tr>
<td>(1) excellent, (2) good, (3) fair, (4) poor, (5) very poor, (6) completely blind</td>
</tr>
<tr>
<td>Item 3</td>
</tr>
<tr>
<td>(1) none of the time, (2) a little of the time, (3) some of the time, (4) most of the time, (5) all of the time</td>
</tr>
<tr>
<td>Item 4</td>
</tr>
<tr>
<td>(1) none, (2) mild, (3) moderate, (4) severe, (5) very severe</td>
</tr>
<tr>
<td>Items 5-14,16,16a,A7,A9</td>
</tr>
<tr>
<td>(1) no difficulty at all, (2) a little difficulty, (3) moderate difficulty, (4) severe difficulty, (5) stopped doing this because of your eyesight, (6) stopped doing this for other reasons or not applicable</td>
</tr>
<tr>
<td>Item 15c</td>
</tr>
<tr>
<td>(1) no difficulty at all, (2) a little difficulty, (3) moderate difficulty, (4) extreme difficulty, (5) stopped driving mainly because of eyesight</td>
</tr>
<tr>
<td>Item 17-19</td>
</tr>
<tr>
<td>(1) all of the time, (2) most of the time, (3) some of the time, (4) a little of the time, (5) none of the time</td>
</tr>
<tr>
<td>Item 20-25,A12,A13</td>
</tr>
<tr>
<td>(1) definitely true, (2) mostly true, (3) not sure, (4) mostly false, (5) definitely false</td>
</tr>
<tr>
<td>Item A1,A2</td>
</tr>
<tr>
<td>(worst) 0 1 2 3 4 5 6 7 8 9 10 (best)</td>
</tr>
<tr>
<td>Item A11ab</td>
</tr>
<tr>
<td>(1) always, (2) most of the time, (3) often, (4) sometimes, (5) never</td>
</tr>
</tbody>
</table>

Independent Mobility Questionnaire (IMQ)

| Item 1-35, 47,48                             |
| N/A, (1) no difficulty, (2) few difficulty, (3) a little difficulty, (4) moderate difficulty, (5) extreme difficulty |
| Item 36-39,43-45                             |
| Yes/No |
| Item 40                                      |
| (1) always, (2) usually, (3) sometimes, (4) never |
| Item 41                                      |
| Yes/No |

Cerebral Visual Disorders questionnaire (CVD)

| Item 2-7,9                                   |
| Yes/No |
| Item 8                                       |
| Yes/No |
| Item 10A-L                                   |
| (0) no problem, (1) rarely a problem, (2) sometimes a problem, (3) often a problem, (4) most of the time a problem |

Spontaneously reported difficulties

The spontaneously reported problems on open-ended questions were grouped by ICF code. For every ICF code, the number of patients reporting at least 1 problem in this area was calculated.

Standardized questionnaires

Because the answer formats of the questionnaire items differed markedly, the different scales were converted into dichotomous scales. The cut-points for the dichotomous scales were based on the conversion rule that every answer stronger than “sometimes a problem” (or words with similar inclination, such as “a little difficulty”) was classified as “difficulty present” (Table 4.2). The items were then grouped by ICF code. Within every ICF code, the number of patients indicating at least one of the problems to be present was determined.

Step 2: In-depth analysis

After determining the number of patients reporting difficulties within the various ICF categories, a more in-depth examination was performed for problems that appear less directly
related to missing part of the visual field. In this analysis, the effect of age on the presence or absence of a reported difficulty was assessed (two-tailed independent samples t-tests). Only results with a $p$-value < .05 were reported.

RESULTS
Step 1: Analysis of reported difficulties
Linking the reported difficulties to the ICF
Classifying the reported difficulties according to the ICF linking rules (Cieza et al., 2005) resulted in 268 concepts for the open-ended question and 248 concepts for the standardized questionnaires. During the process of linking these concepts, in 4 out of 516 concepts, no unanimous decision was reached, and the fourth evaluator was involved in the decision process, resulting in agreement (Table e-1, available on request to author).

Eighty-seven concepts were found not to be covered by the ICF. In order to include these in the analysis, they were grouped based on common sense, resulting in a number of additional categories (Table 4.3). For the answers on the open-ended question, these additional categories were difficulties seeing objects or people in time due to incomplete visual overview, difficulty using the computer, misplacing or knocking over of objects on tables, difficulty choosing suitable positions when sitting together with a group, falling or catching oneself, being easily overstimulated, and bumping the head.

Spontaneously reported difficulties
Among the frequently reported problems were difficulties seeing objects or people in time resulting from incomplete visual overview, as well as problems with orientation, way finding, and mobility (walking around obstacles or people, cycling or driving a car). Reading problems included finding the beginning of the next line or limited endurance. Other activities often experienced as problematic were placing or avoiding knocking over objects on tables, watching television, using the computer, shopping/doing groceries, and performing recreational activities. Patients with HVFD also reported fatigue and emotional disturbances (that is, feeling frustrated, irritable, insecure, scared, or tense) because of their visual disorder. Environmental factors frequently reported to cause difficulties were unfamiliar surroundings, crowded areas, darkness, or inclement weather.

Patients spontaneously reported several activities to be problematic that were not in the questionnaires. These included use of a computer ($n = 10$), riding a bicycle ($n = 7$), placing or avoiding knocking over objects ($n = 6$), writing ($n = 3$), cooking ($n = 2$), doing housework ($n = 1$), and following conversations (when sitting at an unfavorable position at a table; $n = 2$). Patients reported increased fatigability ($n = 7$), difficulty multitasking ($n = 2$), and trouble seeing contrasts ($n = 1$).

Standardized questionnaires
Table 4.3 shows the number of patients who reported problems per ICF category. The results confirm the findings of previous studies that patients with HVFD experience difficulty with finding objects, reading, and mobility. HVFD had a significant impact on participating in society, as the majority of patients reported difficulty with recreation and leisure activities, such as
Table 4.3. Results from the three standardized questionnaires in ICF terms: number and percentage of patients that rated at least one item in the category as problematic. The total number of patients having answered these items is put between parentheses when different from 54. The last column shows the number of items in the questionnaires referring to the category.

<table>
<thead>
<tr>
<th>Category</th>
<th>N (total)</th>
<th>%</th>
<th>N items</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BODY FUNCTIONS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b1 MENTAL FUNCTIONS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b114 Orientation functions</td>
<td>53</td>
<td>98</td>
<td>13</td>
</tr>
<tr>
<td>b1141 Orientation to place</td>
<td>35</td>
<td>65</td>
<td>5</td>
</tr>
<tr>
<td>b152 Emotional functions</td>
<td>51</td>
<td>94</td>
<td>6</td>
</tr>
<tr>
<td>b156 Perceptual functions</td>
<td>29</td>
<td>54</td>
<td>2</td>
</tr>
<tr>
<td>b1565 Visuospatial perception</td>
<td>11 (53)</td>
<td>21</td>
<td>1</td>
</tr>
<tr>
<td>b2 SENSORY FUNCTIONS AND PAIN</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b210 Seeing functions</td>
<td>54</td>
<td>100</td>
<td>41</td>
</tr>
<tr>
<td>b2100 Visual acuity functions</td>
<td>23</td>
<td>43</td>
<td>1</td>
</tr>
<tr>
<td>b21002 Binocular acuity of near vision</td>
<td>23</td>
<td>43</td>
<td>1</td>
</tr>
<tr>
<td>b2102 Quality of vision</td>
<td>47</td>
<td>87</td>
<td>9</td>
</tr>
<tr>
<td>b21020 Light sensitivity</td>
<td>45</td>
<td>83</td>
<td>7</td>
</tr>
<tr>
<td>b21021 Colour vision</td>
<td>11 (53)</td>
<td>21</td>
<td>1</td>
</tr>
<tr>
<td>b21023 Visual picture quality</td>
<td>22</td>
<td>41</td>
<td>1</td>
</tr>
<tr>
<td>b220 Sensations associated with the eye and adjoining structures</td>
<td>11</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>b280 Sensation of pain</td>
<td>11</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>b2801 Pain in body part</td>
<td>11</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td><strong>ACTIVITIES AND PARTICIPATION</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d1 LEARNING AND APPLYING KNOWLEDGE</td>
<td>45</td>
<td>83</td>
<td>8</td>
</tr>
<tr>
<td>d110 Watching</td>
<td>30</td>
<td>56</td>
<td>3</td>
</tr>
<tr>
<td>d166 Reading</td>
<td>43</td>
<td>80</td>
<td>5</td>
</tr>
<tr>
<td>d2 GENERAL TASKS AND DEMANDS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d210 Undertaking a single task</td>
<td>52</td>
<td>96</td>
<td>4</td>
</tr>
</tbody>
</table>
| d2102 Undertaking a single task 
  independently                       | 52        | 96  | 4       |
| d4 MOBILITY                           |           |     |         |
| d450 Walking                         | 53        | 98  | 30      |
| d4502 Walking on different surfaces  | 27 (53)   | 51  | 1       |
| d4503 Walking around obstacles       | 53        | 98  | 15      |
| d455 Moving around                   | 31        | 57  | 6       |
| d4551 Climbing                       | 31        | 57  | 6       |
| d460 Moving around in different 
  locations                           | 46        | 85  | 11      |
| d4600 Moving around within the home  | 22        | 41  | 3       |
| d4601 Moving around within buildings 
  other than home                     | 36        | 67  | 4       |
| d4602 Moving around outside the home 
 and other buildings                  | 43        | 80  | 3       |
| d470 Using transportation            | 21        | 39  | 2       |
| d4702 Using public motorized 
  transportation                       | 21        | 39  | 2       |
| d475 Driving                         | 43 (47)   | 91  | 4       |
| d4751 Driving motorized vehicles     | 43 (47)   | 91  | 4       |
| d5 SELF-CARE                         | 6         | 11  | 1       |
| d540 Dressing                        | 6         | 11  | 1       |
| d6 DOMESTIC LIFE                     |           |     |         |
| d620 Acquisition of goods and services | 52        | 96  | 3       |
| d6200 Shopping                       | 52        | 96  | 3       |
| d7 INTERPERSONAL INTERACTIONS AND 
  RELATIONSHIPS                       |           |     |         |
| d720 Complex interpersonal interactions | 11        | 20  | 1       |
| d7203 Interacting according to social rules | 11 | 20 | 1 |
| d8 MAJOR LIFE AREAS                  |           |     |         |
| d820 School education                | 1 (2)     | 50  | 1       |
| d850 Remunerative employment         | 4 (22)    | 18  | 1       |
Difficulties in daily life reported by HVFD patients

Note: The ICF linking rules prescribe that concepts should be linked to the most precise ICF category. For example, while the concept present level of travel is linked to d4 (mobility), the concept car driving is linked to the more precise level d4751 (driving motorized vehicles). In Table 4.3, the car driving then is counted on level d4751, but also on levels d475 and d4.

*Numbers for Environmental Factors - 1.Products and technology are about whether the products are used, instead of whether use of these products is rated as problematic.

<table>
<thead>
<tr>
<th>Domain</th>
<th>N (total)</th>
<th>%</th>
<th>N items</th>
</tr>
</thead>
<tbody>
<tr>
<td>d9 COMMUNITY, SOCIAL AND CIVIC LIFE</td>
<td>36</td>
<td>67</td>
<td>4</td>
</tr>
<tr>
<td>d920 Recreation and leisure</td>
<td>36</td>
<td>67</td>
<td>4</td>
</tr>
<tr>
<td>d9201 Sports</td>
<td>28</td>
<td>52</td>
<td>1</td>
</tr>
<tr>
<td>d9202 Arts and culture</td>
<td>20</td>
<td>37</td>
<td>1</td>
</tr>
<tr>
<td>d9204 Hobbies</td>
<td>23</td>
<td>43</td>
<td>1</td>
</tr>
<tr>
<td>d9205 Socializing</td>
<td>15</td>
<td>28</td>
<td>1</td>
</tr>
<tr>
<td>ENVIRONMENTAL FACTORS</td>
<td>54</td>
<td>100</td>
<td>20</td>
</tr>
<tr>
<td>e1 PRODUCTS AND TECHNOLOGY *</td>
<td>53</td>
<td>98</td>
<td>3</td>
</tr>
<tr>
<td>e110 Products or substances for personal consumption</td>
<td>51</td>
<td>94</td>
<td>1</td>
</tr>
<tr>
<td>e1101 Drugs (note of author: this refers to medication)</td>
<td>51</td>
<td>94</td>
<td>1</td>
</tr>
<tr>
<td>e120 Products and technology for personal indoor and outdoor mobility and transportation</td>
<td>11</td>
<td>20</td>
<td>1</td>
</tr>
<tr>
<td>e1201 Assistive products and technology for personal indoor and outdoor mobility and ransportation</td>
<td>11</td>
<td>20</td>
<td>1</td>
</tr>
<tr>
<td>e125 Products and technology for communication</td>
<td>21</td>
<td>39</td>
<td>1</td>
</tr>
<tr>
<td>e1251 Assistive products and technology for communication</td>
<td>21</td>
<td>39</td>
<td>1</td>
</tr>
<tr>
<td>e2 NATURAL ENVIRONMENT AND HUMAN-MADE CHANGES TO ENVIRONMENT</td>
<td>49</td>
<td>91</td>
<td>14</td>
</tr>
<tr>
<td>e240 Light</td>
<td>48</td>
<td>89</td>
<td>13</td>
</tr>
<tr>
<td>e2400 Light intensity</td>
<td>48</td>
<td>89</td>
<td>13</td>
</tr>
<tr>
<td>NOT DEFINABLE</td>
<td>18</td>
<td>33</td>
<td>2</td>
</tr>
<tr>
<td>Not definable-general health</td>
<td>18</td>
<td>33</td>
<td>2</td>
</tr>
<tr>
<td>NOT COVERED</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulties seeing objects or people in time due to lack of a complete visual overview</td>
<td>51</td>
<td>94</td>
<td>6</td>
</tr>
<tr>
<td>Falling</td>
<td>35</td>
<td>65</td>
<td>2</td>
</tr>
<tr>
<td>Seeing how people react to things you say</td>
<td>10</td>
<td>19</td>
<td>1</td>
</tr>
<tr>
<td>Forced to rely too much on what other people tell me</td>
<td>11</td>
<td>20</td>
<td>1</td>
</tr>
<tr>
<td>Entertaining friends and family in your home</td>
<td>13</td>
<td>24</td>
<td>1</td>
</tr>
<tr>
<td>Perception of ascending or descending stairwells</td>
<td>24 (53)</td>
<td>45</td>
<td>2</td>
</tr>
</tbody>
</table>

Note: The ICF linking rules prescribe that concepts should be linked to the most precise ICF category. For example, while the concept present level of travel is linked to d4 (mobility), the concept car driving is linked to the more precise level d4751 (driving motorized vehicles). In Table 4.3, the car driving then is counted on level d4751, but also on levels d475 and d4.

*Numbers for Environmental Factors - 1.Products and technology are about whether the products are used, instead of whether use of these products is rated as problematic.

participation in sports, arts and culture, hobbies, and social events.

The ICF specifies 9 domains within the level of activities and participation. On average, patients reported difficulties in 5 (range 2-8) different domains. The number of domains affected was correlated negatively with age ($r = -0.38$, $p = .005$). Younger patients reported difficulties in more domains than older patients. Time since onset of the HVFD was neither related to age ($r = -0.14$, $p = .312$) nor to the number of domains in which difficulties were experienced ($r = .23$, $p = .099$). On average, women experienced difficulties in more domains of activities and participation than men ($t(52) = -3.2.0$, $p = .002$, mean difference 1.1 domain).

Neither side of field defect ($t(52) = 1.32$, $p = .191$) nor type of field defect (hemianopia vs quadrantanopia; $t(52) = 0.01$, $p = .992$) was significantly related to the number of domains affected. Comparisons for gender, side of field defect, and type of field defect should be interpreted with caution because of uneven sample sizes.
**Step 2: In-depth analysis**

It was more problematic to link some repeated problems to missing a portion of the visual field. These were analyzed in more depth.

**Light sensitivity**

The majority of patients (94%) rated at least 1 item on the function light sensitivity (b21020) or the environmental factor light intensity (e2400) as problematic. Fifty-two percent of patients reported that everything seemed darker or that more light was needed when reading. However, 54% reported that they were now more blinded by bright lights. It appeared that 30% of patients experienced both of these problems concurrently. Walking in high glare areas was rated as problematic in 75% of cases, whereas 80% experienced problems walking, driving, or going down steps in dimly lit or dark areas. Combining all questions related to light sensitivity showed that 76% patients experienced problems with bright lights or high glare areas, as well as having increased difficulty seeing in dimly lit or dark areas. Difficulty adjusting to changes in light intensity, for example, when moving from indoor to outdoor, was reported by 56% of patients.

**Color vision**

Twenty-one percent of patients responded to the question on color vision (b21021) that colors did not seem as bright as before their HVFD.

**Perception of depth**

One patient elaborated on the open-ended question that perception of depth, distance, and velocity were disturbed. When all patients were asked whether they experienced problems estimating the height of the next step when using stairs, 21% agreed.

**Negative feelings and thoughts**

The results revealed that HVFD in most patients entailed negative feelings and thoughts (b152). In response to the open-ended question, 35% of patients experienced feelings of insecurity in unknown or busy surroundings or during walking, cycling, or driving. As indicated by the standardized questionnaires, 74% of patients reported worrying about their eyesight at least some of the time (28% most of time, 2% all the time). Half of the patients (50%) experienced feelings of frustration about their eyesight. Worries about doing things because of their eyesight that will embarrass oneself or others were reported by 31%. Eighty-four percent reported to be irritable because of difficulties with vision. Fear of falling was reported by 44%. Sixty-five percent felt unsatisfied with their current ability to travel, and these participants were significantly younger compared to the participants reporting to be satisfied with their traveling abilities ($t(50.4) = -2.341, p = .023$). Regarding physical sensations, 20% of the patients reported pain or discomfort in or around the eyes, preventing them to do the things they wanted to do (b220, b280).
Independence
The majority of patients reported that the HVFD restrained them in performing activities without help from others \((d2102)\). Seventy-two percent indicated that they needed or received an increased amount of help from others because of their visual impairment. Seventy percent felt restricted in walking independently, and 44% indicated that they rarely left the house without someone to accompany them. Those that asked someone to accompany them were found to be significantly younger \((t(52) = -3.391, p = .001)\).

DISCUSSION
We conducted a systematic inventory of the difficulties that 54 patients with HVFD experienced in daily life, expressed in terms of the ICF. To this end, 3 questionnaires often used in studies of visual impairments (NEI-VFQ-25, IMQ, and CVD) were linked to the ICF. Not surprisingly, patients reported difficulties due to deficits in their visual environment and associated feelings of frustration and insecurity. They also reported difficulties that did not seem directly related to missing portions of the visual field, such as disturbed light sensitivity, color perception, and depth perception. Conceivably, the reported difficulties were not related to HVFD specifically but might be a more general result of brain damage. Younger patients described problems in more domains and were less satisfied with their ability to travel independently, compared with older adults. This association was not explained by a confounding effect of time since onset. Possibly, younger patients performed a wider range of activities before onset of the HVFD, making the impact of this deficit more striking.

To the best of our knowledge, there are no other systematic studies of the difficulties experienced by patients with HVFD (see chapter 3), although there are reports describing a more limited scope of difficulties. Most often, these have dealt with patients’ complaints of reading, orientation, and mobility-related activities (Chen et al., 2009; Gassel & Williams, 1963b; Papageorgiou et al., 2007; Trobe et al., 1973; Warren, 2009; Zihl, 1995b; Zihl, 2011). Our results support these findings. Previous reports have indicated that patients with HVFD experience impaired general and vision-related quality of life (Gall, Franke et al., 2010; Papageorgiou et al., 2007; Wagenbreth et al., 2010). We also found that patients with HVFD frequently experienced difficulties with recreation and leisure activities, negative feelings and thoughts, and a feeling of decreased independence. In contrast to our data suggesting that younger patients experience more difficulties in daily life compared with older individuals, other studies did not find an association between age and quality of life (Gall, Franke et al., 2010; Papageorgiou et al., 2007; Wagenbreth et al., 2010) or found poorer quality of life in older patients (Gall, Mueller, Gutlin et al., 2008; Gall et al., 2009). There are no other reports of problems with light sensitivity, color vision, and depth perception, but our study indicates that these problems are frequently experienced by patients with HVFD.

Our aim was not to determine the precise percentage of patients reporting a certain problem but to become aware of the full range of difficulties experienced by patients with HVFD. However, we are aware of the limitations of our report. To begin with, the ICF did not include every conceivable concept. In linking all concepts addressed in the questionnaires to the ICF, 87 (17%) were not covered by the ICF, which was mainly caused by a small number of concepts encountered with high frequency. Next, to enable quantitative assessment, data
were summarized as presence or absence of a problem of at least one of the items within an ICF category. By converting ordinal scales into dichotomous scales, information of the degree of difficulty was lost.

We recognize potential sources of bias affecting generalizability of the results. The different sample sizes for men vs women, left vs right-sided HVFD and quadrantanopia vs hemianopia might be the result of selection bias, possibly related to the exclusion criteria regarding comorbidity. Patients with additional comorbidities, such as neglect, low visual acuity, or impaired oculomotor functioning, might experience a different range of difficulties in daily life. The reported difficulties cannot be assumed to fully generalize to patients not requesting rehabilitation. The current study was performed in the Netherlands. Other countries might provide different challenges for patients with HVFD. Another possible source of bias relates to the answers of the participants. They spontaneously reported a number of problems that were not included in the standardized questionnaires. However, participants did experience problems mentioned in the standardized questionnaires that they had not spontaneously reported. This might suggest an acquiescence bias, possibly leading to false positives on the standardized questionnaires. Nevertheless, acquiescence bias would not account for the relative differences between frequencies of reported difficulties. A final possible source of bias regarding the standardized questionnaires may have come from the fact that not every ICF category was assessed by the same number of items (Table 4.3).

Based on our results, recommendations can be made for professionals involved in assessment of patients with HVFD. In addition to the well-known difficulties experienced by patients with HVFD, a number of additional impairments deserve attention, including disturbed light sensitivity, color perception, and depth perception. These problems might otherwise be overlooked when assessing the patient, as they may not be spontaneously reported. It would be useful to apply both open-ended questions, as well as standardized questionnaires, to this patient population because they were found to be complementary. These recommendations may lead to more effective and appropriate counseling and rehabilitation.

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