Fatigue in adults with visual impairment: the patient perspective

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6th ECPVI 11-09-2016

Project funded by ZonMw-Inzicht
Created with VisionSim app by Braille Institute
Background

Low vision rehabilitation priority list:

1. Reading
2. Writing
3. Acceptance
4. Watching tv
5. Feeling fit

% Fatigue prevalence

- Visually impaired adults: N=247
- Controls: N=176
Qualitative study: goals

- Perceived symptoms of fatigue?
- Perceived causes of fatigue?
- Experienced consequences of fatigue?
- Coping with fatigue?
Sampling

Inclusion criteria:
1. 18+
2. Dutch language
3. Fatigued
4. Currently not being treated for MS, CFS, psychiatric disorder or cancer

21 interested
17 informed consent
N = 16
Methods

**Topic (fatigue):**

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<th>Example question</th>
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<tr>
<td>(1) Symptoms</td>
<td><em>When did the first symptoms of fatigue started to occur?</em></td>
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<td>(2) Causes</td>
<td><em>What do you think causes the fatigue?</em></td>
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<td>(3) Consequences</td>
<td><em>What are the emotional consequences of fatigue?</em></td>
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<td>(4) Coping strategies</td>
<td><em>How did you learn to cope with your fatigue?</em></td>
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**Methods:**
- Fully structured survey
- Semi-structured interview
- Unstructured conversation
Analysis

**Transcription**
- Audiotaped
- Verbatim

**Open coding**
- Labelling data

**Axial coding**
- Identifying relationships
- Based on open codes

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Cognitive functioning

- Concentration
- Attention
- Working memory
Sample (N=16)

Mean age = 51

Other causes of vision loss:
Glaucoma, ablatio retinae, neurosarcoidosis, congenital cataract, usher syndrome, ocular albinism, retinoblastoma, leber congenital amaurosis, choroideremia, diabetic retinopathy
Experienced symptoms of fatigue

- Mental fatigue: $N=13$
- Everyday symptom: $N=11$
- Physical fatigue: $N=9$
- Need to sleep: $N=5$
Perceived causes of fatigue

- High cognitive load
- Effort for visual perception
- Light intensity
- Dysfunctional emotion regulation
High cognitive load

N=15

Quote participant:
(58 years, Leber’s congenital amaurosis)

“You’re getting fatigued because you’re in a constant state of processing stimuli, that’s pretty exhausting. It’s really difficult to filter out the right kind of information, sometimes everything is crowding in on you.”
Effort for visual perception

Quote participant:
(41 year, ocular albinism)

“So your eye is constantly trying to focus, trying to get a sharp image which cannot be obtained. That's really tiresome, it's like a camera when it can't find a point of focus.”
Light intensity

Quote participant:
(54 years, diabetic retinopathy)

“For me it’s also exhausting whenever it gets dark. It’s as if you end up in an introverted state which requires more energy to snap out of.”
Dysfunctional emotion regulation

Quote participant: (30 years, congenital cataract)

“What also comes into play for me are my negative thoughts about my visual impairment. What would other people think whenever I’m walking around with my white cane? Those thoughts take an awful lot of energy as well.”
Perceived consequences of fatigue

- Social roles and participation
- Emotional functioning
- Cognitive functioning
- Daily activities
Social roles and participation

Quote participant:
(38 years, Usher syndrome)

“Because of my fatigue I’m no longer able to participate in society.”
Emotional functioning

Quote participant: (54 years, diabetic retinopathy)

“Well, I become gloomy whenever I’m really tired and I start overestimating my own responsibilities, even though they aren’t my own responsibilities at all sometimes.”
Cognitive functioning

*N=14*

Quote participant:
(77 years, retinitis pigmentosa)

“I find it extremely difficult to really focus on what another is saying in a company, I just let it slide when I’m tired”
Coping strategies to deal with fatigue

- Rest and relaxation
- External support
- Physical and social activities
- Acceptance
Rest and relaxation

Quote participant:
(42 years, glaucoma)

“I take a nap almost every day. Well napping..., you just want to rest, to close your eyes for a while..”
Quote participant: (58 years, Leber congenital amaurosis)

“I’ve been to the rehabilitation centre for a couple of years at some time in the past, and this certainly contributed to the process of accepting my fatigue.”
Physical and social activities

Quote participant:
(38 years, Usher syndrome)

“I like to be physically active. I just like to go for a walk or go cycling, I also really enjoy drinking a beer with my friends, it gives me energy.”
Quote participant: (Female, 58 years, Leber congenital amaurosis)

“You could view fatigue as an enemy but you can also choose to deal with it. That would make it more difficult because fighting against it won’t help me anyway.”
Therefore fatigue may be central to the way patients react and adapt to vision loss!
Discussion

Similarities with the fatigue experience of other patient populations with regard to fatigue symptoms, consequences and coping

Fatigue is caused by specific factors related to vision loss!
Patients use own resources to cope with fatigue, but these strategies seem unsufficient.

General fatigue interventions might not be sufficient because of the specific factors related to vision loss.

Currently no evidence-based interventions available for vision-loss related fatigue.

Future research is warranted, interventions should be designed with a focus on the population-specific factors of fatigue.

References:
Symbols: [www.thenounproject.com](http://www.thenounproject.com)
Vision loss simulation: VisionSim app by Braille Institute

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