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Fatigue among adults with visual impairments

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Abstract

Background: Previously conducted research suggests that fatigue is associated with many chronic diseases, such as visual impairment. Therefore this study investigates the health care provider's point of view on a. the prevalence and severity, b. potential causes, c. the impact of fatigue on the everyday life of patients and d. coping strategies. **Method:** Two focus groups ($n_1 = 8$, $n_2 = 6$) have been created. The members include professionals for the physical and mental treatment of visually impaired patients who were invited to join a discussion guided by a semi-structured interview scheme. The resulting transcripts have been analyzed via the method of categorization **Results:** Participants agreed upon the fact that visual impairments make the most parts of patients' everyday life very challenging and consequently lead to a state of fatigue. Furthermore fatigue seems to have a negative effect on several dimensions of the patients' lives, e.g. physical and social aspects. Also, effective and less effective coping strategies have been identified during the discussion sessions.

Conclusion: The current study was able to approve the hypotheses of visual impairments causing fatigue and having a tremendous impact on the patients' life. Further, it provides insight into the prevalence, severity and coping strategies. All of this can be used for future research in several directions and to establish intervention programs.

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The World Health Organization (WHO) recorded an increase in life expectancy for both genders throughout the years 1990 to 2013, especially in developed countries like The Netherlands, Germany or the United States (WHO, n.d.). Coming along with this increase is the numerical growth in age-related diseases like dementia (WHO, 2011). Another example of an age-related disease includes the topic in question – visual impairments. According to the WHO, there are two groups that are at high risk to develop visual impairments. The first one consists of people in low-income settings and the second group are people aged 50 or older. More than 65% of the people suffering from visual impairments (ranging from moderate impairments to blindness) are 50 years or older, even though they make up only around 20% of the world's total population (WHO, 2014).

Several studies further indicate negative effects related to visual impairments. Among others, problems like increased aggression, a lower self-concept and self-determination may arise when suffering visual impairments (Wolff, 1965; Lieberman & Robinson, 2004; Beaty, 1991). In particular, the article of Mojon-Azzi, Sousa-Poza and Mojon (2008) investigates the most common effects on the quality of life of people having these problems. According to their study, visual impairments not only affect the eyesight but also increase the probability for depression, decrease the concentration levels and negatively influence the perceived well-being in general. In addition to that, the results clearly showed that visually impaired people are more likely to suffer from fatigue compared to a reference group with excellent eyesight.

Since visual impairments are usually chronic, the concept of its symptoms might be comparable to other chronic diseases. Here, one study (Chahin et al., 2015) indicated that visual impairments among multiple sclerosis (MS) patients are associated with physical fatigue. Furthermore, a meta-study investigated the consequences of fatigue in cancer patients. The results clearly show that fatigue can have and most probably will have a substantial negative impact on emotional, social and economic dimensions. Most importantly,

the researcher found out that fatigue can reduce the patient's willingness and capacity to consult professional help, to describe the problems they have, and in general to follow the corresponding treatment (Curt, 2000). Additionally, Nikolaus, Bode, Taal and van de Laar (2009) have conducted research regarding fatigue among patients with rheumatoid arthritis (RA) and found out that fatigue is a commonly perceived symptom among these patients. Especially certain circumstances like having to fulfill multiple different roles (e.g. working while also being a mother and a housewife) highly amplifies the extent of fatigue and its consequences. Similar results were found in another study of fatigue among RA patients (Repping-Wuts, Uitterhoeve, van Riel, van Achterberg, 2008). Even though these studies investigated cancer, RA, and MS patients, the perceived fatigue and its consequences might partly be the same for people suffering fatigue caused by visual impairments. The determinants and causes might differ, but still, the likelihood to develop fatigue, the expression and impact of fatigue are expected to be comparable. Summing up, Curt, Nikolaus et al. and Repping-Wuts et al. found out that fatigue leads to emotional, social and economic confinements. Mojon-Azzi et al. similarly found out that, besides fatigue, precisely these symptoms are reported by people with visual impairments. Taking a look at all the research findings together, fatigue appears to be a crucial aspect and might even act as a mediator between the visual impairments and the reported reduction of the quality of life in other dimensions. These studies indicate that fatigue is caused by chronic diseases like cancer or RA. Aspects like frequent treatments and the physical burden of the respective disease itself can have exhausting effects. Especially patients with visual impairments might be sensitive to symptoms of fatigue since even daily activities like reading or traveling can become challenging and therefore exhausting (West et al., 2002). On top of that, these challenges might cause compensation behavior to kick in (Bäckman & Dixon, 1992), which again, might have exhausting effects.

Due to on the one hand striking indications that fatigue is a major aspect of chronic diseases like visual impairments and on the other hand the low amount of research conducted in that direction, this bachelor thesis will qualitatively investigate the physicians' point of view, using data sets from a study conducted by the VUmc Amsterdam. The VUmc used the concept of focus groups to examine the notions and opinions of experienced health care providers. This group included professionals of Dutch low vision rehabilitation centers. The group of experts can offer a more rational and independent point of view to the situation making it possible to gain a good overview of the situation. Furthermore, due to their knowledge, experience and to a certain degree higher distance to the problem they might be able to see causes or relations that the patient himself might not see. For example, a patient could consider the fatigue caused by visual impairments, whereas a professional thinks they are unrelated - or the opposite might be the case. In addition to that, the experience and medical knowledge makes it easier to distinguish between different factors, thus not overly weighing specific factors while disregarding others, e.g. knowing that specific medication might have a tiring effect.

When having the goal of investigating opinions of experts, focus groups are very advantageous. On the one hand, participants are encouraged to share their notions, potentially helping other participants to think of certain aspects they might have forgotten to mention in personal interviews. Additionally, there is room for discussion, which might elicit certain opinions, or even whole topics and help to clarify certain statements or issues (Baarda et al., 2013; Kitzinger, 1995). Furthermore, by agreeing upon or mentioning certain aspects more often, the participants highlight which aspects they consider fitting and important, helping the analyzer to understand and grasp the significance.

Qualitatively analyzing the statements of the discussion round – compared to quantitative data collection – has the advantage that it provides more individual and detailed

information, allowing people to explain and explicate their opinions, perceptions and why they think the way they do. This is necessary for this research topic because perceptions of the level of fatigue and its relation to other parts of their life (e.g. social or emotional components) can differ extremely, not only from patient to patient, but also from professional to professional. Additionally, detailed information is crucial to fully understand the (perceived) relations between visual impairments and fatigue.

The topic of visual impairment and the related fatigue affects a huge number of people. And due to the fatal consequences fatigue can have on a person's life, it is important to further investigate the causes, consequences and factors that relate to fatigue among visually impaired people.

This study will take a step forward into improving the patient's situation during both the treatment sessions and the everyday life. Finding out more about the causes and relations between visual impairments and fatigue will help to understand the patients' needs and how a treatment has to be shaped to be most efficient. For example the timing of the treatment sessions might be adjusted, e.g. early in the morning in case the patient feels more energetic at that time. Due to the focus on the group of professionals, especially the treatment can be altered depending on the given statements. This might include things like how to approach a visually impaired patient, how much attention he or she needs, how the treatment process will be scheduled or structured and more. Summing up, further investigating the problem of fatigue among visually impaired adults will open up ways to support the great number of people suffering from this form of fatigue.

The goal of this study is to get a structured overview over whether the health care providers believe visual impairments to be a contributing factor to and a cause of fatigue. Based on previously conducted research the hypothesis is that the professionals will see visual impairments of any kind as an important contributor to fatigue by putting extra strain

on patients, through for example compensation behavior. Besides, this study wants to examine more about what the professionals think potential consequences of fatigue are on the patient's everyday life, e.g. are there specific activities (like job or social interactions) that can no longer be carried out (as well as before)? As indicated in other studies, it is expected that chronic fatigue highly affects the patient's (everyday) life on several dimensions. Another important aspect of this problem is whether or not there are successful coping strategies and to what extent patients and professionals are using them. This study will thus explore the professional's point of view on four aspects: the severity of the perceived fatigue, potential causes, the impact of fatigue on the everyday life and the coping process. Gaining insight and knowledge concerning this matter might further help to establish potential interventions targeting the health care providers to improve their awareness of the problem and their knowledge about how to approach and treat these patients.

Method

Focus groups were established in order to ask health care providers about the prevalence and severity of fatigue among visually impaired patients, what kind of potential causes and determinants of fatigue there are, what the impact of fatigue looks like and how they think patients cope with the situation.

Participants

The first focus group consisted of $n=8$ participants, working in different sectors of the Dutch low vision rehabilitation center 'Koninklijke Visio'. The participants' jobs include mainly occupational therapists, psychologists, and trainers for alternative ways to handle daily challenges related to low vision. They are thus experts for accompanying and supervising patients, physically and mentally. The members of the second group are in comparable positions, but working for the Dutch low vision rehabilitation center called 'Bartiméus'. Just as in group one, there are supervising functions, trainers for coping

behavior, and psychologists. Noteworthy here is that one of the professionals of group two is a visually impaired person herself.

Sampling

In order to gather participants, the leading researcher sent a request to all of his contact persons at the two Dutch low vision rehabilitation centers called 'Bartiméus' and 'Koninklijke Visio'. Additionally a request was published in the intranet of Bartiméus and Visio. In both cases, the researcher provided sufficient information about the research itself and asked for a participation in the focus groups. Conditions for participation include experience with and affinity for fatigue among their patients.

Procedure and Instruments

The two focus group sessions were following a relatively strict structure when it comes to both its content and its time scheduling. In total, the session was about three hours long, starting with welcoming the participants and letting each of them introduce themselves. Right after, the leading researcher presented the ongoing project in terms of describing and explaining the procedure, the reasons, goals and possible gains. The introduction of participants and the introduction of the project took approximately thirty minutes, leaving enough time for every participant to ask questions. The next two hours and fifteen minutes included the actual discussion, following a set of in total six parts, or main-questions, prepared beforehand. Each of the parts dealt with a specific domain and aims for specific information. In case the respondents did not provide the information by themselves, there were also follow-up questions prepared in order to gain the necessary data.

The first question asks the participant to think of and describe an example of a patient that also reports problems regarding fatigue. Follow-up questions, among others, deal with aspects that are specific for the visual impairment and reasons for mentioning precisely this example (instead of another one).

The second question examines the experience and severity of fatigue. More precisely, the question asks for an estimation of the extent of the fatigue-related complaints among the participant's patients. This question thus tries to examine how big of a role fatigue plays in the patient's lives, how the process looks like when it comes to development and whether it is on a constant level or of varying intensity. Are there conditions or situations where fatigue is especially troublesome or acceptable, how do patients experience the fatigue in the long run, how does a normal week or month look like (regarding fatigue)? These are the questions within the second part the researchers want to have answered.

The third part of the discussion structure is about the causes of fatigue, asking for potential external and internal factors, thus trying to find determinants for fatigue such as disruptions of the biological clock, sleeping disorders, inactivity or over-activity, overburdening oneself, and more. Additionally, we wanted to know to what extent and how the visual impairment contributes to the fatigue and whether or not the participants think that the lack of acuteness of vision leads to (stressful) compensation behavior like increased concentration levels in order to work correctly with the lowered level of visual stimuli or placing higher strains on other sensory organs to compensate for the lack in vision. Compensation behavior might become a source for exhaustion this way.

The fourth part includes the impact of fatigue on the everyday life of the patients. What kind of influence does fatigue have on normal activities like reading and writing, keeping up with the personal agenda, on the patient's mobility (driving a car, riding a bicycle, using public transports), on the social life or the job.

The fifth part deals with coping processes used by patients. Are there specific physical or mental activities or methods to decrease the influence of fatigue? Where do the patients get energy from? For example hobbies or social contacts might be a source for that. How and to what extent have patients learned to live with their fatigue-related set of problems?

In the end the sixth and last part of the discussion structure tests or questions the knowledge of the professionals. The status of knowledge regarding fatigue is of great importance in order to assess the validity of given statements. Furthermore, we want to know whether there are any practical advices or methods used to support the patients and whether there are specific aspects seen as highly important and therefore requiring a great amount of attention.

Right after the six main parts have been examined and discussed, the researcher summarizes the most important findings and listens to potential questions. Additionally, the seating arrangements are saved and the researcher thanks each respondent for their participation.

The instrument, meaning the structure that was used during the discussion rounds, is based on the questionnaire the researchers used to interview their participants, supplemented by questions specific for health care professionals, e.g. how much knowledge they have regarding fatigue. This questionnaire was designed on the basis of scientific research (Bode, Hoek & Köhle, in prep.) and each question was formulated in consideration with experts (Dr. C. Bode & R. van Nispen). Moreover, the time scheduling left enough time to enable the participants to fully explicate their notions. It therefore respects the voice of the researched – which is crucial in qualitative research.

The whole process was recorded with an audio device.

Analyzing the Data

Using the program Atlas Ti, the transcripts were analyzed in a way that highlights aspects that are mentioned more often or agreed upon by many participants, the so-called method of categorization. During the analysis of the transcripts, statements that provided an answer or significant content to one of the main questions were noted, according to the category they belong to. Here, unimportant or unrelated statements were disregarded. The analysis thus

delivered a set of categories about a.klammern lassen es nicht ganz so aussehen als wäre der satz zu ende the severity of fatigue, b. the causes, determinants and factors, c. the impact of fatigue on the everyday life, and d. coping processes. For each main question apart, these statements were then further grouped on the basis of common key components. For instance, if different statements referred to a patient being physically exhausted, the subcategory of ‘impact on a physical level’ was created. Likewise, there were for example several statements referring to emotions felt by the patient. These were then grouped under the name of ‘impact on an emotional level’. Partly, these subcategories were explicitly defined by the respondents, by e.g. literally stating that there are different dimensions of causes and naming these dimensions.

For the process of analysis as such, this means that the semi-structured interview scheme led to a pre-defined categorization and is therefore regarded as top-down. The sub categories, however, were acquired through bottom-up analysis. This means that specific statements led to the creation of higher-ranking categories, as opposed to having subcategories defining the information that will be regarded or disregarded. A code schema can also be found in the Appendix (Table 1.).

Results

This section includes the results of both focus groups taken together, focusing on statements that were agreed upon by many of the participants and that did not lead to mentionable objection, thus representing a certain degree of significance and importance. Due to the interdependency of the four broad categories, there will also be a paragraph explicating the relationship between those. Debatable or less agreed upon statements will be reported at the end of the result section. The schema of the categories, or codes, can be found in the Appendix.

Severity and Experience

During the discussion over the severity of fatigue and the experience patients have with it, the participants agreed that “achtig tot negentig procent” of their visually impaired patients also report symptoms of fatigue. Explained is this high prevalence on the basis of eyesight being “een heel dominant systeem”. Eyesight is basically used for everything people do during the wake time, so that difficulties using this system results in general difficulties during the daily routine. Additionally, the onset and progress of fatigue was describes as “geleidelijk en steeds erger wordend”. Due to the slow onset, patients often do not recognize the symptoms early enough, often not until they are heavily exhausted (“ik vraag er vaak naar [wanneer de klachten voor het eerst ontstaan zijn], maar mensen komen daar zelf niet zo snel mee [...] tenzij meteen met burn-out merk je het dan vaak, dan is het allemaal mis gegaan”).

With regard to specific situations that can influence the extent of fatigue felt by the patients in the one or the other direction, health professionals listed many different aspects. Firstly, there is a mental aspect, meaning that acceptance of the visual impairment plays an important role. According to the participants, fatigue complaints are decreasing when patients accept their impairment, mainly due to the fact that they then begin to lower their expectations they set for themselves (“dan valt in een keer de last af [...], dan zie je wel vermoeidheid teruglopen [...]. Maar dat is dan puur omdat ze minder eisen aan zichzelf stellen”).

Secondly, acceptance often leads to the willingness to ask for help, which again, lowers the pressure on the patient (“[...] dan komt het punt waar je om hulp gaat vragen”). Thus, accepting leads to less demanding situations regarding many different activities. Thirdly, there are some activities that help patients decrease the perceived fatigue. “Deze zijn bijvoorbeeld naar boeken luisteren of sociale contacten.” Fourthly, as patients keep going without taking a break, for example when doing sport or working, the fatigue seems to be less prevalent “er zijn wel wat clienten die zeggen van ‘ja als ik ga zitten juist wel, dus ga ik niet

zitten.’ Dan kun je het wel uitstellen [...]’ On the opposing side, there are also activities or situations that worsen the fatigue. These include all activities that put strain onto the patients’ eyes, for example reading, working with the computer, mobility (riding a car or traveling by train), or shopping. Additionally, standing still worsens the perception of fatigue because doing nothing often allows the fatigue to fully kick in (“er zijn wel wat cliënten die zeggen van ‘ja als ik ga zitten juist wel, dus ga ik niet zitten.’”).

Causes and Contributing Factors

When it comes to the causes of fatigue, the participants highly agreed that visual impairments do contribute to fatigue (“Denken jullie dat de visuele beperking een rol speelt bij vermoeidheid?” – all of the respondents answered with “ja!”). The high prevalence of 80-90% is also an indication for a causal relationship. One of the participants gave a dead-on summary: “je moet je voorstellen... dat je ziet slecht, dus alle activiteiten duren langer, je moet er veel meer energie insteken, en je moet er ook nog veel langer van bijkomen... dat past nooit in diezelfde dag, terwijl je wel dezelfde dingen moet doen in zo’n dag als een goed ziende..dan kan het niet anders als dat je daar ontzettend vermoeid van raakt... als je diezelfde activiteiten in een dag moet doen”. However, there is a discrimination to be made with regard to different types of fatigue. According to the health professionals, there is a physical, a mental and an emotional level of fatigue.

Causes of physical fatigue. As causes for physical fatigue, participants mentioned many different aspects: many activities need more time (“dan kost het weer meer tijd [...] wat dan ook meer vermoeidheid veroorzaakt”), visual strains when e.g. reading, trying to fulfill someone’s role (e.g. being a mother) or coping behavior (“[copingsgedrag]... als het te veel wordt zorgt het alleen maar voor meer vermoeidheid”). A lack of physical activities or doing (too much) sport (“vooral gebrek aan beweging, maar te veel kan ook”) is also of influence. Especially patients with a progressive disease want to do all sorts of things as long

as they are able to (“mensen met een progressieve aandoening, die zo veel mogelijk willen doen zo lang ze het nog kunnen zien”), but this is often too much for them. Another point is also trying to be part of e.g. a group, thus going along with activities that put too much strain on oneself to e.g. not get socially isolated (“dan hebben ze gewoon nog goed ziende vrienden die dan nog [van alles ondernemen] en dan is het heel moeilijk om ‘nee’ te zeggen,... dan ben jij de spellbreaker”).

Causes of mental fatigue. The health professionals pointed out that there is a type of fatigue stemming from your mental attitude. For example “dingen blijven doen zoals voor de ziekte” or “niet accepteren van visuele beperkingen en de vermoeidheid” can become causes for mental or physical fatigue, because it will lead to counterproductive behavior. Additionally, the pressure of being forced to constantly adapt to a progressive disease (and in many cases, it is progressive) puts high strains on the patient (“je altijd nieuw aanpassen [...] dat is een cruciale punt”). A very influential factor are the unconscious processes healthy people do not even recognize. For example, having a mental representation of the faces of people you are talking to becomes increasingly difficult for visually impaired people. But due to the fact “dat het nog maar steeds geprobeerd wordt”, fatigue increases as a consequence. Another necessity for visually impaired people, compared to healthy people, is that they have to memorize a lot of things because writing them down as a reminder does not work anymore. These might include appointments, prices of products you buy, plans for upcoming activities and more (“ja in die zin onthouden mensen veel meer ‘tuurlijk, dat kan natuurlijk ook een deel van de vermoeidheid zijn”). A huge factor is also “dat dingen niet meer van zelfsprekend zijn”. For people suffering visual impairments many common activities become challenging so that you can no longer ‘just do things’ – “over alles moet nagedacht worden”. Neither is doing more than one activity at the same time possible, because a high degree of concentration is necessary to accomplish even one of them. Lastly, greater changes of life

circumstances can have a tremendously exhausting effect: “bij sommige zie je dat ook wel als ze naar het hoger beroepsonderwijs bijv. gaan, dat is ook zo’n moment – van voortgezet naar beroepsonderwijs, en vooral als ze naar een HBO of Universiteit, dan kan het in een keer helemaal...dan krakt het in een keer helemaal in”.

Causes of emotional fatigue. Becoming visually impaired is often associated with negative emotions, according to the health professionals. For example fear is one of the emotions they encounter regularly. Fear on the one hand of the progress of the disease, thus for the future state or situation of seeing even less than now. On the other hand, there are situations that can cause fear. For example walking down a street when it is dark outside becomes especially frightening when your eyesight is impaired (“[...] dan krijgt zij enorme last van angst”). Another often perceived emotion is frustration or anger, “als ze ‘normale’ dingen willen doen maar niet meer kunnen doen”. Furthermore, patients, when standing still without distraction, often enter a state of thoughtfulness over their current situation, recognizing how many things got so difficult to carry out and how easy it has been when their eyes were still working correctly, which often leads to a sad or even depressive mood. These emotions are basically consequences of the visual impairments, but taken together, negative emotions can also put high strains on patients, leaving them exhausted (“paniek of angst kost dan ook weer energie”; “te gaan piekeren is uitputtend en dan komt daar nog frustratie of boosheid of wat dan ook bij”).

Social factors. One last contributing factor is the reaction of the social environment. Contributing to fatigue might be a boss that does not show any understanding of or sympathy for the patient’s situation (of being visually impaired or exhausted) and therefore creating a workload that is too high for the patient. Similarly, the patient’s colleagues can be cooperative and helpful, or the exact opposite, where the latter would worsen the symptoms of fatigue (“en ook een heel belangrijk iets is hoe de omgeving reageert, hoe de werkgever er

is, of die daar nog druk oplegd of dat die de ruimte geeft om langzaam te reageren, ook het begrip van collega's, of die willen meewerken als de prestatie naar beneden gaat”).

Impact of Fatigue on Patients

Generally speaking, fatigue leads to the patient being forced to change his behavior. For example finding less demanding ways to carry out daily activities. Aside from that, the professionals' estimation of the impact fatigue has on visually impaired people can also be divided into a physical, a mental and an emotional aspect. Especially true for the physical dimension, but also fitting for the others, is that certain activities can often no longer be carried out. If that is not the case, these activities can become unpleasant because they become very demanding. Furthermore, there was an additional category described, which deals with the social life and related factors. Important to note here though, is that the health professionals pointed out that it is extremely “moeilijk om tussen vermoeidheid en visuele beperking te onderscheiden. Dat kunnen vaak ook de patienten zelf niet.”.

Impact on a physical dimension. According to the health professionals, participants frequently report complaints such as “hoofdpijn, pijn aan de ogen, trillingen en een gevoel van ‘ik moet slapen’” during the day. The participants further encounter patients that are physically exhausted, mainly caused by activities that put strain on the eyes (e.g. reading, working with the computer). This often results in an avoidance of many physically demanding activities like sport, taking a walk or others “([lichamelijke activiteiten] die sort activiteiten gaan ze dan vaak vermijden”), because they leave the patient too exhausted.

Impact on a mental dimension. Among mental effects, concentration and attention problems were frequently reported as symptoms (“concentratie problemen... en aandacht”). Even burn-out symptoms (mainly among people with a job) play a role [“vaak zie je da nook burn-out terug”]. Additionally, these problems then often lead to “angst om fouten te maken”. Especially when having a job, the concentration and attention problems can lead to mistakes

that can have negative consequences, so that either avoidance behavior kicks in or fear is present during the process.

Impact on an emotional dimension. To a great extent the fear of making mistakes plays an important role and often leads to the avoidance of specific activities (“[...] dan zijn ze daar bang voor en gaan het vermijden”). In addition to that, the fatigue often leads to frustration and anger due to the inability to do the things you want, because one is simply too exhausted. The problems and complications patients experience also often result in a loss of confidence in one’s own abilities and capacities (“ze gaan dan het vertrouwen verliezen”). Consequently, a feeling of insecurity develops in patients, e.g. when they are outside to do the shopping, traveling by train or during their work (“ja.. zeker onzekerheid...”).

Feeling fatigued on a regular basis also often results in a depressive attitude or mood (“[...] dat ze last hebben van neerslachtige stemming”).

Impact on the social life. According to the health professionals, the social life suffers extremely due to the fatigue. Patients, over the course of time, “laten een soort apathie zien, en dat leidt dan ook vaak tot terugtrekken [uit het sociale leven]”. Additionally, the state of exhaustion often leads to the inability to participate in social events like parties, having a coffee party with friends or others. Fatigue then results in social isolation.

Mainly rooting from the visual impairment, but also partly from the fatigue, people are not able to execute common activities alone. This means, they have to depend on other people’s help. The independence alone already limits your range of possible activities, but also knowing that one is dependent of others is often seen as an unpleasing situation, which then elicits frustration or sadness (“[mensen worden dan afhankelijker [...]] en dat leidt ook vaak weer tot frustratie of verdriet”).

The last important aspect of the impact of fatigue is that it slows down compensation or coping behavior because patients are simply too exhausted. This might even include

following the treatment of the actual visual impairment (“coping is dan ook nog vaak een probleem. Leren dingen anders te doen vereist natuurlijk ook energie”). Learning how to do things in a non-visual way or using other coping strategies requires energy to begin with. This energy might not be there when feeling too exhausted.

Coping

Coping strategies, whether successful or not, can be divided into three subcategories. These are a. coping focused on visual impairments, b. focused on adapting to the new situation of being fatigued and lastly, distracting oneself from the fatigue.

Coping focused on visual impairments. Health professionals mentioned a long list of coping strategies. Most of the coping strategies however relate to the visual impairment. If for example a visually impaired person learns to work or act non-visually, the problems of the visual impairment are of course weakened. This way, tasks become less demanding and less challenging which also helps decreasing the fatigue (“leren non-visueel te werken... dan zie je inderdaad ook wel de vermoeidheid terug lopen”).

Coping focused on adapting. Strategies directly focused on the fatigue first and foremost require a conscious process of acceptance. The health professionals often encounter patients that try to ignore or euphemize the fatigue and “ze leven gewoon zo alsof er niets aan de hand is”. According to all of the professionals, however, acceptance is the most important aspect of an effective coping. Accepting the fatigue enables the patient to work with an enormous amount of subsequent coping strategies. These include “[...] regelmatig pauze hebben [...]”, “hun eigen activiteiten analyseren en dan leren hoe het meer energie kost en hoe het minder energie kost”, “ontspanningsoefeningen met experts”, “[...] alternatieven gebruiken, bijv. naar een boek luisteren in plaats van lezen.” “Om hulp vragen” and working with the fatigue in a sense of knowing one’s limits: “[bijv. als het om een groter event gaat,

zoals vakantie met vrienden] 'ik weet gewoon dat die klachten gaan komen, ik plan erom heen. Ook gewoon daarvoor en daarna weinig activiteit”.

Distraction. Lastly, there is the possibility of mainly physical distraction. Doing sport is an often used and to a certain degree effective coping strategy (“sporten doen mensen ook heel vaak. Door dat sporten krijgen zij wel energie”). Also participating in special activities like paragliding can distract from the fatigue and restore energy (“het zijn niet alledagse dingen maar het zijn activiteiten waar mensen of gewoon inderdaad een keer met een bullie een wandeling kunnen maken of fietsen op de tandem” and “ja dat geeft dan wel energie...paragliden ook”).

Relations between the Four Broad Categories

Severity is an aspect of its own. However, the other three categories, causes, impact, and coping also relate to one another. For example many of the things belonging to the category ‘impact’ can become causes. This is mainly when the impact is not accepted by the participant. For example to the category ‘impact’ belongs ‘being forced to do things in a different way’ (less energy demanding), but if this is not (effectively) done, it becomes a cause for fatigue or at least a maintaining factor. Likewise continuously trying to do things that are usually no longer or hardly possible can cause fatigue or worsen its perceived extent (e.g. working full-time).

Many coping strategies are also very demanding. Learning new ways e.g. non-visual usually requires an investment of energy, which can be exhausting. Also doing sport can be quite effective and helpful, but from a certain point onwards, it only becomes another cause for physical tiredness and therefore contributes to the feeling of fatigue.

Debatable Statements

During the discussion sessions, there were three themes that created contradiction among the participants. The first one was that one respondent mentioned an unbalanced nutrition as

contributor to fatigue. Even though the other participants agreed upon that statement, it was not clear whether an unbalanced nutrition is characteristic for the population in question. One argument supporting the thesis was that doing the shopping as well as cooking can become challenging for patients, which might result in a less healthy diet. However, the rest of the participants did not feel like there was a connection in a sense that visual impairments contributes to bad nutrition habits.

The second theme deals with hallucinations. Some of the patients of the first focus group did indeed encounter patients that reported hallucinations as a symptom. In fact, the estimation of prevalence was as high as 15%. It was estimated that trying to distinguish between reality and hallucination and the psychological aspect of thinking “ben ik gek?” have a tiring effect. However, throughout the discussion, it did not become clear what causes hallucinations and whether or not it is a contributing factor to (or impact of) fatigue. Furthermore, the given number of 15% was not agreed upon. In fact, there were many participants having never heard of hallucinations from their patients.

On the basis of a certain research article, one of the participants theorized that the tension, strain and pressure patients feel lead to a high cortisol level in the patient’s blood. This above-average cortisol level increases over time “omdat ze het opbouwen en opbouwen en opbouwen”. However, this statement did not find approval by other participants and was solely based on a study unrelated to fatigue or visual impairments.

Discussion

The goal of this study was first and foremost to answer the question of whether visual impairments cause or contribute to fatigue, and if so, to what extent. This study additionally addresses the aspects of prevalence, perceived severity, the impact of fatigue on a patient’s life and coping strategies. According to the sample, visual impairments contribute very strongly to fatigue, thus supporting the hypothesis. The visual system is the most dominant

source of perception and having to face impairments in this system leads to difficulties with basically every task or activity. There is thus a constant work overload present for visually impaired patients which leaves them exhausted. Furthermore, health care professionals pointed out that fatigue has an enormously high prevalence (80-90% of the patients) and strongly limits the capacities, abilities and therefore the activities patients can carry out. This limitation can be observed on different dimensions, which are a. physical, b. mental, and c. social. Also negative emotions like frustration or depressive moods are associated with fatigue. The professionals thus also support the second hypothesis that fatigue shows a strong, negative impact on a patient's life.

This is the first study researching the relationship between visual impairments and fatigue. However, there are several studies presenting results regarding fatigue among patients with other chronic diseases. Concerning the prevalence, for example Chahin et al. (2015) found fatigue to be present in only 48% of MS patients. The difference to the 80-90% found in this study might be due to MS being a disease with a wide range of the severity of symptoms. The prevalence of fatigue, however, increases if MS symptoms include visual impairments, so that the findings of Chahin et al. (2015) support this study's results. Also Curt (2000) found fatigue to be present in 76-78% of cancer patients that followed chemotherapy.

Health care professionals described fatigue as having a slow onset and progressive process. This is in accordance to the visual impairments. Many visual impairing diseases show a slow onset and slow progression. In RA patients, for example Repping-Wuts et al. (2008) found that fatigue has a sudden onset. Even though RA also usually has a slow onset, the perception of pain is often sudden. It is theorized that the extent of pain suddenly reaches an intolerable degree. Pain then becomes a main contributor to fatigue

Visual impairments often lead to limitations and difficulties in everyday tasks and activities. These activities then require a lot more effort, which is often considered as exhausting. It is thus the consequences of the visual impairments that create fatigue. In contrast, Curt (2000) demonstrates that in cancer patients, the chemotherapy is the greatest contributor to fatigue. Here, it is thus the treatment of cancer that causes fatigue. Aside from that, there are studies supporting the findings of this article, by showing that fatigue is much more likely to be present in visually impaired people, therefore showing the influence of visual impairments on the available energy level in patients (see e.g. Mojon-Azzi et al., 2008; Chahin et al., 2015).

With regard to the impact fatigue has on patients, it was surprising that health care professionals perceived and explicitly mentioned a physical fatigue that shows impact on solely physical activities (e.g. limitations when doing sport or other physical movements, headache, or pain). Only Chahin et al. (2015) did find a physical dimension as well. Aside from that, there are no studies indicating a focus on physical dimensions of fatigue.

Fatigue mostly results in avoidance behavior, because patients simply feel too exhausted to do what they want to or plan to do. Hewlett et al. (2005) was also able to observe avoidance behavior due to fatigue among RA patients, but to a lesser degree (e.g. avoiding only especially tiring tasks in contrast to everyday activities). Wiborg et al. (2011) found comparable avoidance behaviors in patients with chronic fatigue syndrome (CFS). This gives the impression that the fatigue elicited by visual impairments is comparable to CFS, which clearly demonstrates its impact on patients.

Especially detailed was the description of emotional states patients find themselves in, according to the health care professionals. Other studies indicate depressive moods among cancer patients (Curt, 2000), frustration, problems regarding relationships, irritability and loss of control (Hewlett et al, 2005) among RA patients and a positive association between fatigue

and depression and pain (Reuter et al, 2006). However, a description of the emotional states this detailed, including causes, relationships and consequences, could not be found within the existing literature. The findings of this study are thus in accordance with existing literature, but also provide new information regarding how fatigue exactly relates to e.g. frustration or depressive moods.

With regard to coping strategies, Mock et al. (2000) indicate that informed and supportive experts are a key factor, which is also supported by the finding that being able to talk about the fatigue and related problems can be very helpful (Ream et al. 2002). Aside from that, Reuter et al. (2006) further point out that there is only a weak correlation between coping and the perceived extent of fatigue in breast cancer patients. In contrast to these three studies, the health care professionals used in this study provide a great amount of potential coping strategies, effective or ineffective (e.g. sport, euphemizing, denial), especially the active role of the patient is stressed, whereas Mock et al. and Ream et al. describe a more passive role. That physical exercises like aerobic can help is also demonstrated in other studies (Dimeo, Stieglitz, Novelli-Fischer, Fetscher, Keul, 1999). Furthermore, detailed information regarding strategies that seem to have a positive effect is provided (e.g. training sessions with professionals, relaxation exercises, accepting the fatigue and adjusting one's lifestyle to the new situation). Also battling the visual impairment itself and reducing its consequences seems to be very successful. However, the professionals pointed out that many coping strategies are applied unconsciously by the patient (e.g. euphemizing and denial). The other four studies described here directly addressed patients. In contrast, the professionals used in this study have knowledge, experience and a certain distance to their patients which enables them to objectively observe and evaluate the coping strategies patients use. Therefore, they might be aware of aspects that patients themselves are not.

An important and surprising finding is also that the two focus groups independent of each other provided very homogenous information. This suggests that fatigue among visually impaired patients has a very homogenous appearance. Another possible explanation could be that the professionals have a similar background in a sense of academic education and working area. They are both working for comparable Dutch low vision rehabilitation centers. All of these aspects together might lead to a similar focus or selective attention.

This study provides unique insight into visual impairments and resulting symptoms of fatigue, especially regarding the causal relationship between the two, because it is the first study researching this. Additionally, many of the findings not only support existing results of fatigue among patients with other chronic diseases, but also extend these results when it comes to how detailed the information is. How precisely visual impairments cause fatigue and how fatigue affects a patient's life has not been described so detailed, yet. These new insights might help future studies researching this topic. On the basis of the results, quantitative measurement instruments might be developed (e.g. questionnaires) or frameworks that will help professionals and patients to understand and change the situation. The similarities to fatigue caused by other chronic diseases also indicate that these results might not be limited to visually impaired persons.

The results of this study could potentially be used to increase the awareness of healthcare providers so that they do not (unintendedly) disregard fatigue symptoms. Also raising the understanding and awareness of healthcare professionals might lead to more empathy for their patients, which is commonly seen as helpful for the treatment (Fields et al., 2010). The information gained can also help adjusting the treatment of low vision rehabilitation centers by e.g. offering trainings for coping strategies or developing more successful interventions for patients. Also demonstrating to what extent fatigue negatively impacts a patient might lead to adjustments on the side of insurance agencies, so that they are

willing to pay for according treatments. All these potential changes might eventually increase the patient's well-being by reducing the prevalence, severity, and impact of fatigue.

Limitations

Content-wise, there is one thing especially important to note. The professionals pointed out that neither they nor the patients themselves are able to strictly and correctly distinguish between fatigue and visual impairments regarding the impact. That is, potential limitations faced by patients are often caused by both, visual impairments and fatigue and it is almost impossible to determine which of the two has the greater influence. This means, that the impact of only fatigue could not be measured validly.

It has always been problematic to generalize results gained by qualitative research (Fields, 2010), which limits the usability of this research. Especially with a sample size of $n = 14$. However, the goal of gaining insight into the relationship between visual impairments and fatigue plus corresponding consequences and coping methods has been accomplished. In addition to that, this study investigated the view of healthcare professionals. This means, the participants were talking about their patients, which means that their frame of reference is extended greatly. The fact that professionals referred to all of their patients weakens the limitation of a low generalizability and the small sample size.

Further, the sample includes a very homogenous group. All professionals were chosen on the basis of an affinity with fatigue and are working in similar working areas. Their education and therefore their opinions regarding fatigue might thus be relatively alike. Also the patients they are talking about are all in a similar situation of treatment. Experts with a different education or patients that are in a different situation (e.g. not receiving any treatment) might deliver different results.

The last limiting effect on the results is that the transcriber is not a native speaker in Dutch, so that errors or misunderstandings might have occurred during the transcription and

analysis of text fragments. To compensate for that, a native speaker checked and supported the process of transcription.

Recommendations

Further research is necessary in order to check or clarify results that stand in contrast to previously conducted research. Investigating these differences is important to gain unambiguous insights and clear answers to the respective questions. Also attempting to distinguish as strictly as possible between fatigue and visual impairments regarding the impact will be helpful for future interventions. Aside from that, the data provides good insight into key aspects of fatigue among visually impaired patients. This could be used to develop questionnaires or other quantitative measurement instruments. Applying these to a high number of people will make generalization possible. This also opens up the opportunity to take into account other factors that might be of value. For example demographic variables or the SES might deliver interesting results. In addition to that, frameworks or concepts could be worked out on the basis of the information found in this study in order to present guidelines for coping strategies for both, healthcare professionals and patients. This way, ineffective or even counterproductive coping strategies might be prevented.

Conclusion

Summing up, the results clearly support the pre-established hypotheses and are also in accordance with many previously conducted studies, even though these studies used patients suffering from different chronic diseases. These results, the results that differed from older research and those that were new can be used for further research. Furthermore, they might help healthcare providers raising their own awareness and understanding of fatigue, while also providing guidelines for how to deal with fatigued patients. Despite the limitations, this study was successful in answering the leading questions and moreover provides very detailed information about underlying relationships between fatigue and visual impairments.

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Appendix

Tables

Table 1.

Code Schema

First level code	Second level code	Description/Examples	Quotations
Severity & prevalence	Onset and process	Slow and progressive	Langzaam en progressief
	Situations/activities that weaken fatigue	Sports, listening to books, social contacts	Naar boeken luisteren i.p.v. lezen; sporten is ook wat wat ze heel vaak doen
	Situations/activities that worsen fatigue	Too much sport, activities that demand eyesight	[sport...] maar te veel kan ook. Ook activiteiten zoals lezen of met de computer werken... je ogen gebruiken
Causes	Physical fatigue	Physically (especially eyesight) demanding activities (reading, working with the computer)	Sporten, lezen of de computer gebruiken, ...
	Mental fatigue	Process of acceptance or denial, not willing to adept	Dan blijven ze dingen doen zoals voor de ziekte; je altijd nieuw aanpassen
	Emotional fatigue	Lowered capabilities lead to sadness, anger, fear	Frustratie merk je vaak op of woede kan oo;. en dan gaan ze snel bang worden

Impact	External factors	Reaction of social environment (understanding boss/family?)	en ook een heel belangrijk iets is hoe de omgeving reageert
	Physical dimension	Headache, feeling of needing to sleep, physical exhaustion	Hoofdpijn, gevoel van 'ik moet slapen', ...
	Mental dimension	Concentration and attention problems	Concentratie en attentie problemen ook hoor
	Emotional dimension	Fear, frustration, anger, insecurity	Angst om fouten te maken; frustratie; of ook onzekerheid
	Social life	Social isolation, not being able to participate in social events	Leven is heel gejaagd.. en dat niet meer kunnen meedoen dan..
Coping	Focused on visual impairment	non-visual working/acting	Non-visueel werken helpt heel vaak..dan zie je ook de vermoeidheid teruglopen
	Focused on adapting	Acceptation processes, learning how tasks cost less energy, denial/euphemizing	De acceptatie speelt een heel grote rol; verbloemen, negeren zie je ook vaak terug
	Distraction	Activities that make the fatigue appear less prevalent	Sporten; of dingen blijven doen.. als je gaat stilstaan dan komt het allemaal

First and second level codes with their respective meaning or examples

Measurement Instruments

Gesprekshandleiding focusgroepen: “Ontwikkeling van een interventie voor het doelmatig behandelen van vermoeidheidsklachten van volwassenen met een visuele beperking”

Focusgroep

Deelnemers: Medewerkers van de revalidatiecentra Visio en Bartiméus vanuit verschillende disciplines die ervaring hebben vanuit hun werk met visuele beperkte volwassenen met vermoeidheidsklachten.

Doel: Ter inventarisatie van bestaande kennis en adviezen voor het verminderen van vermoeidheidsklachten bij visuele beperkte volwassenen.

Onderwerpen: De Ernst en beleving van Vermoeidheid, oorzaken en gevolgen van Vermoeidheid, coping met Vermoeidheid en bestaande kennis en adviezen over Vermoeidheid van de betrokken professionals

Agenda:

1.	Welkom	10:00
2.	Voorstelronde deelnemers	10:10
3.	Presentatie project “Vermoeidheid bij visueel beperkte volwassenen” door W. Schakel	10:10 - 10:30
4.	Start focusgroep:	10:30-
		12:45
	a. Algemene openingsvraag	10:30

	b. Ernst en beleving van Vermoeidheid	10:50
	c. Oorzaken van Vermoeidheid	11:10
	d. Pauze	11:30
	e. Impact van Vermoeidheid op het dagelijks leven	11:45
	f. Coping met Vermoeidheid	12:05
	g. Kennis van professionals over Vermoeidheid	12:25
5.	Uitnodigen cliënten voor kwalitatieve onderzoek	12:45
6.	Afsluiting	12:50

Welkom:

Welkom, fijn dat jullie er zijn. Ik wil jullie bedanken dat jullie hier vandaag aanwezig willen zijn. Mijn naam is Wouter Schakel en ik ben de uitvoerende onderzoeker van het project. Ik zal het gesprek vandaag samen leiden samen met mijn college Ruth van Nispen, hoofdonderzoeker van het project.

Jullie hebben je aangemeld voor deze focusgroep op basis van jullie ervaring met visueel beperkte volwassenen met vermoeidheidsproblematiek. Het doel van deze focusgroep is om te inventariseren welke kennis er bestaat over vermoeidheidsklachten bij visueel beperkte volwassenen bij de revalidatiecentra. Daarnaast zijn we benieuwd of er al adviezen worden gegeven aan cliënten voor het verminderen van de vermoeidheidsklachten. Deze informatie is ontzettend waardevol voor ons onderzoek en gebruiken we voor het ontwikkelen van een interventie ter vermindering van Vermoeidheid bij visueel beperkte volwassenen.

De bijeenkomst vandaag duurt maximaal 3 uur. Wij stellen jullie een aantal vragen en het is hierbij de bedoeling dat jullie met elkaar over deze onderwerpen praten en discussiëren. Er zijn geen goede of foute antwoorden mogelijk, elke bijdrage is waardevol. Alvorens we beginnen met de discussie zal ik straks eerst beginnen met een korte presentatie over het project.

Doorgaans nemen we focusgroepen altijd op. Dat helpt ons bij een goede uitwerking. Gaan jullie hiermee akkoord?

Voorstelronde deelnemers:

Om te beginnen willen we graag weten wie jullie zien.

Zou je je kort willen voorstellen, en vertellen:

- Wat je naam is?
- Wat je functie is?

- Voor hoe lang werken jullie al met deze doelgroep?

Start focusgroep

Opstellen van discussieregels en verwachtingen:

Slechts een person tegelijk neemt het woord en elke bijdrage is waardevol. Alle standpunten voor de discussie zijn belangrijk. De sessie wordt opgenomen om te garanderen dat alle opmerkingen meegenomen worden.

Leg uit dat het gaat om een onderzoek, verzoek de groepsleden niet door elkaar te praten, vraag om toestemming als je het gesprek opneemt, leg uit dat de informatie strikt vertrouwelijk is en geef aan dat je geïnteresseerd bent in positief en negatief commentaar, leg uit dat deelnemers het niet met elkaar eens hoeven te worden, vraag deelnemers respect te tonen voor elkaars mening, voorkom algemene uitspraken zoals we weten toch allemaal etc, geef aan dat de deelnemers medeverantwoordelijk zijn voor het groepsproces.

Het interview:

Hoofdvraag 1. Noem één aansprekend voorbeeld van een visuele beperkte client met vermoeidheidsproblematiek

Vervolg vragen:

- Welke aspecten hiervan zijn specifiek voor de visuele beperking?
- Waarom heb je dit opgeschreven?
- Kun je vertellen waarom je hieraan denkt?
- Kun je hier wat meer uitleg over geven?
- Welke punten zijn voor jou het meest belangrijk?
- Welke punten zijn voor jou minder belangrijk?

Deel 2: Ernst en beleving van vermoeidheid

Hoofdvraag 2. In welke mate hebben de visuele beperkte volwassenen die jullie tegenkomen in de revalidatiecentra last van vermoeidheidsklachten?

Discussievragen:

1. Hoe groot is de rol van Vermoeidheid in het leven van visuele beperkte volwassenen?
 - a. Is het altijd aanwezig?
2. Hoe is het beloop van vermoeidheidsklachten bij visuele beperkte volwassenen?
 - a. Op welk moment zijn de klachten het eerst ontstaan?
 - b. Op welke momenten zijn de klachten het sterkst en het zwakst?
3. Hoe wordt Vermoeidheid door visuele beperkte volwassenen ervaren?
 - a. Hoe ziet een normale week qua Vermoeidheid eruit?

Deel 3: Oorzaken van vermoeidheid

Hoofdvraag 3. Wat zijn volgens jullie mogelijke oorzaken van Vermoeidheid bij visuele beperkte volwassenen?

Discussievragen:

1. Wat zijn volgens jullie mogelijke externe oorzaken van Vermoeidheid bij visuele beperkte volwassenen?
 - a. Externe factoren: visuele beperking, slaapproblemen, co-morbide ziekten/handicaps
 - b. Interne factoren: inactiviteit/overactiviteit, overschrijden van persoonlijke grenzen, onregelmatig ritme
 - c. Onderscheid Ton Schilderman:
 - i. Verstoring biologische klok (met slaapproblemen en chronische Vermoeidheid ten gevolge)
 - ii. Non- en deels visuele handelingen kosten een veelvoud aan energie

- iii. Energie die (het onder controle houden van) emoties en irritaties kosten die visueel beperkten geregeld in hun aanpassingsproces, en in hun dagelijks leven moeten spenderen
2. Welke invloed denken jullie dat de visuele beperking heft op de ervaren Vermoeidheid?
 3. Denken jullie dat er specifieke visus-gerelateerde problemen zijn die bijdragen aan vermoeidheidsklachten?
 - a. Vermoeidheid van de ogen, overconcentratie voor het waarnemen van restprikkel, compensatiegedrag (zie vraag 4), overbelasting andere zintuigen, inactiviteit ten gevolge van visuele beperking
 4. Zijn er bijvoorbeeld activiteiten of handelingen die cliënten anders moeten uitvoeren door hun visuele beperking die kunnen resulteren in Vermoeidheid?
 - a. Huishoudelijke taken, werk, beperkte mobiliteit, verzorging
 5. Welke rol denken jullie dat slap & ritme spelen bij vermoeidheidsklachten van visueel beperkte volwassenen?
 - a. Hebben de cliënten die last hebben van vermoeidheidsproblematiek ook klachten met betrekking tot hun slaap?
 - b. Hoe veel uur per nacht slapen ze en verschilt dit met de situatie voor de visuele beperking of het ontstaan van de Vermoeidheid?
 - c. Hoe is de kwaliteit van hun slap, is er sprake van moeite met inslapen of worden ze regelmatig wakker?
 - d. Hoe verloopt het opstaan, wordt men uitgerust wakker of kost het veel moeite om uit bed te komen?
 - e. Zijn er klachten van slaperigheid overdag, zoals behoefte aan dutjes of onweerstaanbare slaapaanvallen?

- f. Rol licht i.v.m. het resetten van de biologische klok?

Deel 4: Impact van Vermoeidheid op het dagelijks leven

Hoofdvraag 4. Welke invloed heft Vermoeidheid op het leven van visueel beperkte volwassenen?

Discussievragen:

1. Welke invloed heft Vermoeidheid op het leven van visueel beperkte volwassenen op het gebied van:
 - a. Leren en toepassen van kennis: lezen, schrijven
 - b. Administratie en bijhouden van de agenda
 - c. Communicatie: computergebruik, telefoneren, luisteren, lezen, schrijven
 - d. Mobiliteit: thuis, binnen, buiten, openbaar vervoer
 - e. Zelfverzorging: eten en drinken, persoonlijke verzorging, medicijngebruik
 - f. Huishoudelijke taken:
 - g. Werk of studie:
 - h. Sociale leven:

Deel 5: Coping met Vermoeidheid

Hoofdvraag 5. In welke mate denken jullie dat visueel beperkte volwassenen controle ervaren over hun vermoeidheidsklachten?

Discussievragen:

1. Zijn er activiteiten waardoor visueel beperkte volwassenen meer Vermoeidheid ervaren?
 - a. Fysieke activiteit, specifieke dagelijkse bezigheden

- b. Houding ten gevolge van visuele beperking
- 2. Zijn er activiteiten waardoor visueel beperkte volwassenen juist minder Vermoeidheid ervaren?
 - a. Fysieke activiteit
 - b. Mentale activiteit
- 3. Waar krijgen visueel beperkte volwassenen energie van?
 - a. Bijvoorbeeld hobby's, contact met vrienden en familie
- 4. Op welke manier hebben visueel beperkte volwassenen leren omgaan met hun vermoeidheidsklachten?
 - a. Is er sprake van een acceptatieproces, worden de klachten erkend?
 - b. Hebben ze bijvoorbeeld werk, ritme of dagelijkse bezigheden aangepast aan hun Vermoeidheid?
 - c. Hebben ze dit zelf geleerd of door advies vanuit hulpverlening en omgeving?
- 5. Welke invloed hebben de vermoeidheidsproblemen van visuele beperkte volwassenen op hun omgeving?
 - a. Zijn er naasten die huishoudelijke taken overnemen?
 - b. Zijn er naasten (deels) gestopt met werk voor het opnemen van de mantelzorg?
- 6. Hoe gaat de omgeving (familie, vrienden en naasten) om met de vermoeidheidsklachten van de cliënt?
 - a. Wordt Vermoeidheid geaccepteerd?
 - b. Is er begrip voor het fenomeen?

Deel 6: Kennis van professionals over Vermoeidheid

Hoofdvraag 6. Welke kennis bestaat er binnen Visio en Bartiméus over Vermoeidheid bij een visuele beperking?

Discussievragen:

1. Is iedereen binnen de revalidatiecentra voldoende op de hoogte en zich bewust van de vermoeidheidsproblematiek bij visueel beperkte cliënten?
2. Voelen jullie je competent in het behandelen en begeleiden van visueel beperkte cliënten met vermoeidheidsproblematiek?
3. Welke praktische oplossingen of adviezen worden er gegeven voor het verminderen van vermoeidheidsklachten bij visueel beperkte cliënten?
4. Wat zijn volgens jullie aandachtspunten waarmee we rekening moeten houden bij het ontwikkelen van een interventie voor het tegengaan van vermoeidheidsklachten bij visueel beperkte volwassenen?