# **Bachelor Thesis:**

Fatigue and how it is related to goal-management strategies and the vision-related quality of life in visually impaired people

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## Abstract

In the Netherlands, about 300.000 people have a visual impairment and this number is expected to increase until 2020 (Epidemiologie van visuele beperkingen en een demografische verkenning - Verslagen - ZonMw, 2017). A common symptom that is experienced by visually impaired people is fatigue and despite this, there is scarcely knowledge regarding fatigue among this population group (Bruijning, 2013). Therefore, the purpose of this study was to explore the roles of goal-management strategies and the visionrelated quality of life for fatigue severity and fatigue impact among 247 visually impaired people from the Netherlands. The people were asked to fill in several questionnaires via phone with an interviewer. For this cross-sectional study, the data of the Fatigue Adjustment Scale (FAS), the Modified Fatigue Impact Scale (MFIS), the Flexible Goal Adjustment Scale and the Low Vision Quality of Life questionnaire were analysed with correlational - and four hierarchical regression analyses. The first model included demographics, that showed to be significantly related to fatigue severity respectively the impact of fatigue, and the four goalmanagement strategies: goal adjustment, goal pursuit, goal reengagement and goal disengagement. The second model also included the demographics and vision-related quality of life. The results showed that the goal adjustment strategy played a significant role in the severity of fatigue as well as in the impact of fatigue within this sample. People who adjusted their goals experienced less severe fatigue and less impact of fatigue on their daily life. In contrast, a high usage of the goal disengagement strategy was not inevitably related to less severe fatigue respectively usage of the goal reengagement strategy to less impact of fatigue on daily life. These results are in concordance with past literature for people with RA from Arends, Bode, Van de Laar and Taal (2013). Nevertheless, the study from Boerner and Wang (2012) stressed that also the usage of goal disengagement and goal reengagement strategies led to better mental health for visually impaired people. Therefore, future research should try to explore the goal dis - and goal reengagement variables further by using for example another instrument that is better able to measure these strategies. Low-vision related quality of life contributed to more severe fatigue as well as to more impact of fatigue. However, it has to be mentioned that the relations and the explained variances were low in general and therefore it is recommended to conduct a longitudinal study with more variables that could explain fatigue in visually impaired people like for instance physical activity.

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## Introduction

The statement: "Fatigue is just there, and at some point there is a lot of acceptance. You also adjust your life accordingly to it, 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." (Schakel et al., in press, p.9) was made by a women who suffers from leber congenital amaurosis which is a disease that can result in complete vision loss (Bainbridge et al., 2008). This case reflects common experienced symptoms in people who have a visual impairment, namely the symptoms of fatigue. Visually impaired people mentioned a high rehabilitation need for fatigue as it was shown by Bruijning (2013). However, there is only limited research with regard to fatigue in visually impaired people. That is the reason why the following thesis tried to explore the possible determinants of fatigue in visually impaired people. Thereby the focus lies on a dimension of the psychological concept of self-regulating behavior, so called goal-management and a physical concept, namely the vision-related quality of life.

According to Baumeister, "self-regulation refers to the self's capacity to alter and change itself and its states, particularly so as to bring them into line with standards such as norms, goals, ideas, or rules." (Baumeister, 2010, p. 158). Moreover, self-regulation is known to be a voluntary and deliberative rather than an automatic behaviour. Therefore, this psychological concept is understood as the control of the individual to engage in goal directed activity or in the modification of the own behaviour. The conscious and deliberative character of this kind of behaviour makes it interesting for health psychologists whose primary goal it is to promote health-directed behaviour of people (Hagger, 2010). A closely related concept is the concept of self-management. The self-management concept is though widely used in literature with regard to dealing with a chronic disease and to improve patients' outcomes. This concept introduced a development to a form of health-care wherein the patient is in the center of it, the so called person-centred care (Udlis, 2011). One could ask why this is the case. In fact, living with a chronic disease means a day-to-day management of the consequences that go along with a chronic disease. This day-to-day management is defined as a life-task and has to be conducted by the patient himself instead of surrounding care -givers. It should consist of health-promoting activities like the taking of medication or engaging in physical practices or in brief, the adjustment and adaption to the chronic disease (Lorig & Holman, 2003; Arends, Bode, Taal, & v.d.Laar, 2016). For this, different abilities are needed like the ability to make appropriate, personal health-promoting decisions or the ability to mobilize own resources and skills (Lorig & Holman, 2003). Based on the described facts, it is

not surprising that nowadays health intervention programmes are strongly targeted at self-regulating behaviour like self-management (Hagger, 2010).

As already the quote of Baumeister (2010) says, personal goals are one motivating, striving force that bring people to the concept of self-regulation, respectively selfmanagement when talking about people with a chronic disease. That is the case because people constantly try to improve their current condition and well-being (Lindenberg, 2013). Personal goals and the attainment of these play a huge role when it comes to the well-being of people because, in fact, one of an often set personal goal is the reaching of well-being and life satisfaction. Furthermore, personal goals represent the future orientation and give people a sort of life meaning but also influence peoples' present emotions (Emmons, 2003). The opinion of Emmons (2003) is in concordance with the theory of Brandtstädter and Rothermund (2002) who described a two-process framework, namely the assimilative and the accommodative mode when talking about goals in life. These two emphasised the ambivalent character of goals because on the one hand they can provide the personal meaning in life that was also mentioned by Emmons (2003). On the other hand, not being able to reach the own set personal goals can result in dissatisfaction and even depression (Brandtstädter & Rothermund, 2002). Life can be unstable and uncertain, therefore people have to deal with a possible unattainability of the own personal goals throughout their life. The assimilative mode describes that the person changes something in the current situation so that as a consequence the current situation fits more adequately with the own personal goal which was set. On the other hand, the accommodative mode means the adjustment of a future goal so that it fits with the current situation. Therefore, these two modes represent a sort of dilemma, called the stability-flexibility dilemma. On the one hand, people should have high commitment to the own personal goals to strive for them in order to reach life-satisfaction. On the other hand, if the commitment to the own goal is too high, people will not be flexible enough to distance themselves from this goal, to adjust or even to switch to another. Brandtstädter and Rothermund (2002) formulated a model wherein cognitive sets as well as contextual-related sets are involved that determine which mode the person is likely to choose. Nevertheless, these two modes interact through the whole lifespan. Especially the accommodative mode can be seen as a buffer against the feeling of loss and depression when the maintenance of the goal is not possible anymore due to different issues like for instance personal exhaustion or the unavailability of personal resources (Brandtstädter & Rothermund, 2002). Wrosch, Schreier, Carver and Schulz (2003) also emphasised the positive potential that a disengagement of personal goals can have for the individual. However, Wrosch et al. (2003)

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stated that there is a need for further studies within the field of goal disengagement that are directed towards for instance promoting and hindering variables in order to explain the usefulness of disengagement in comparison to goal maintenance.

Due to the fact that goal-management and self-management are also strongly related because both belong to the concept of self-regulating behaviour, several recent studies tried to explain the relationship and impact of the goal-management strategies and the personal health of people who deal with a chronic disease. The study of Arends, Bode, Taal and van de Laar (2016) reformulated the model of Brandtstädter and Rothermund (2002) through adding *goal disengagement* as a facet of goal adjustment and thus, broaden the accommodative mode. Furthermore, these researchers added *goal reengagement* from Wrosch et al. (2003) which should be seen as an exploration and commitment of alternative goals as a parallel process to disengaging from old ones. This integrated model is based on a cross-sectional study which was conducted three years earlier by the same researchers wherein the results indicated that goal disengagement rather belongs to the concept of goal adjustment than being a concept on its own (Arends, Bode, Taal, & van de Laar, 2013). Figure 1 shows the dimensions of self-regulation including the four goal-management strategies.



FIGURE 1 Arrangement of the psychological concept of self-regulation

The goal of the longitudinal study with the integrated model from Arends et al. from 2016 was to examine how the strategies are related to psychological health for people with polyarthritis. Psychological health which is also understood as adaption to chronic disease and the experience of a quality of life including for instance low levels of depression, low anxiety and life satisfaction. Within this study of Arends et al. (2016), three clusters of goal-management were researched, namely *moderate engagement, broad goal management repertoire* and *holding on*. For instance, participants with high scores on all four described

strategies were assigned to the second cluster. The results showed that a broad repertoire of goal-management strategies led to better psychological health for the participants over time. This means that the ability of flexible and simultaneous use of all strategies profits the psychological health of people with polyarthritis more than being focused on one strategy. What has been described so far, self-management behaviour which belongs to self-regulating behaviour should be taken into account to improve the quality of life of people who suffer from a long-term condition. Furthermore, recent studies showed that especially goal-management as a dimension of self-management has a positive impact on the psychological health and therefore its relation to psychological health in different long-term conditions should be studied in the future.

Moreover, it was found that self-management also has a positive impact on fatigue (Hewlett et al., (2011). Furthermore, fatigue can have an impact on the quality of life. Thereby it has to be differentiated between the perceived severity and the impact of fatigue. Fatigue severity and the impact of fatigue are correlated to the concept of quality of life and therefore to psychological health. However, these two variables are usually seen separate from each other because they are not inevitably correlated. That is the case because impact of fatigue on daily life is for instance relative to life conditions like age or work situation (Kos, Nagels, D'hooghe, Duportail, & Kerckhofs, 2006) but also relative to coping strategies as it was shown by Hewlett et al. (2011). In fact, both variables, perceived severity as well as the impact of the fatigue were reduced by self-management within an intervention for people who suffer from rheumatoid arthritis (Hewlett et al., (2011). Thus, once again the importance of self-management for people with a long-term condition is emphasised to support people's quality of life which is also related to fatigue.

Although there is no common definition of fatigue in literature it is often described as a feeling of tiredness and the inability to fulfil daily life tasks due to weakness (Jelsness-Jørgensen, Bernklev, Henriksen, Torp, & Moum, 2011). In addition to this, research among long-term illnesses showed similarities in the description of experiences of fatigue like the unfamiliarity with the own body, loss of control and the inability to explain these feelings to others (Eilertsen, Ormstad, Kirkevold, Mengshoel, Söderberg, & Olsson, 2015). Because of the subjective character of fatigue, studies merely rely on self-reported questionnaires like how severe the fatigue is or how huge the impact of the fatigue is (Jelsness-Jørgensen et al., 2011). Due to its complex relations to clinical and psychosocial factors and often unclear relations to pain for instance, fatigue is difficult to treat (Hewlett et al., 2011).

As emphasised before, especially people with a visual impairment report a high

rehabilitation need for fatigue. The term visual impairment stands for people with a lower vision (less than 30 percent) or even blind people with a vision of less than five percent. The prevalence rate for people with a visual impairment in the Netherlands was approximately 298.000 in 2005 but an increase up to 354.000 is estimated for 2020 (Epidemiologie van visuele beperkingen en een demografische verkenning - Verslagen – ZonMw, 2017). In general, visually impaired people have more difficulties to fulfil daily life tasks, are more dependent on others and at risk of loneliness (Asplund, 2000). Therefore, it is not surprising that these people often report a lower quality of life. One could ask which factors explain the experienced fatigue in visually impaired people. For instance, available literature stresses that visually impaired people often have sleep disturbances because less exposure to daylight can disorganize the circadian circle (Asplund, 2000). The study from van Rijn, Joosse and Kerkhof (2014) mentioned the possibility that fatigue could be a consequence of these sleepdisturbances. It is important to point out that there is also a difference between men and women that women suffer more often from sleep-disturbances. Thus, it could be possible that women are at more risk of fatigue because of more sleep-disturbances due to their visual impairment. Furthermore, the high amount of concentration that people with visual impairment have to spend to process visual stimuli can also result in fatigue. In general, matters are complicated by the fact that the physical activity that is often advised to fatigued people to reduce fatigue, is difficult to fulfil for people who have such a visual impairment (Asplund, 2000).

The described outcomes in the previous paragraph emphasised the role of visual impairment in fatigue. Due to the known relation of fatigue and quality of life, it is necessary to examine the vision-related quality of life. Moreover, research in Germany showed that even a mild visual impairment can be associated with low quality of life (Finger et al, 2011). Thus, especially people who are diagnosed with a visual-impairment according to the definition criteria mentioned earlier are at risk of low quality of life. Furthermore, literature showed that the underlying eye-condition that causes the visual impairment is not that influencing like the severity of the visual impairment. This means that especially the severity of the visual impairment can cause less quality of life (Chia, Wang, Rochtchina, Smith, Cumming, & Mitchell, 2004). Therefore, less vision-related quality of life might result in more fatigue.



FIGURE 2 Illustration of the possible contributors to fatigue severity and perceived impact of fatigue

Although coping strategies and self-management is a possibility to successfully reduce fatigue, as it was described in the previous paragraphs, there is a research gap between coping strategies and its influence on fatigue for people with a visual impairment (Schakel et al., in press). That is the reason why the following research questions had an explorative character. The aim of this study was to figure out whether the described four goal-management strategies contribute to perceived severity and impact of fatigue in people with a visual impairment. Furthermore, the vision-related quality of life was also taken into account. It could be suspected that the vision-related quality of life is also a contributor to severity and/or impact of fatigue. The research questions sounded as follows:

Do the goal-management strategies (goal maintenance, goal adjustment, goal disengagement and goal reengagement) contribute to the perceived fatigue severity and perceived impact of fatigue in visually impaired people? What is the role of vision-related quality of life in the perceived fatigue severity and perceived impact of fatigue in visually impaired people?

Despite the explorative character, it was hypothesised that the goal-management strategies are negatively related to perceived severity and impact of fatigue in visually impaired people because of earlier results from Arends et al. (2016) for people with polyarthritis. Moreover, it was hypothesised that goal adjustment, goal disengagement and goal reengagement is related to less severity and perceived impact of fatigue than goal maintenance because of a study from Boerner and Wang (2012) wherein a general accommodative coping style led to better mental health in people with a visual impairment. With regard to the second research question, it was hypothesised that low vision-related quality of life is related to more severe fatigue severity because of the mentioned possible negative impact on sleep and cognitive capacity that visual impairment can have. The role of vision-related quality of life in impact of fatigue is also examined but this might also be explained by other variables like age and work situation.

## Methods

#### Sample

For this quantitative study, the data of 247 patients from two low vision and two multidisciplinary low vision rehabilitation centers (Koninklijke Visio and Bartiméus) in the Netherlands were used. People who made use of a low vision rehabilitation programme in 2015 or 2016 received randomly an invitation letter. In total, 1281 invitation letters were sent out by Koninklijke Visio and Bartiméus instead of the researchers themselves due to privacy regulations. The final sample consisted of 247 people. Further inclusion criteria for this study were that the patients were at least 18 years old and that they had a sufficient mastery degree of the Dutch language. The most common eye-disease among this sample with 19% was the macula degeneration disease. Within this sample, there were more women than men. The average age was about 57 years. Nearly the whole sample was from Dutch origin. The average education level was about 12 years. Moreover, nearly the half of the sample stated to have one comorbidity.

The following table summarises the demographics for this research sample (see table 1).

Demographic Variable	Distribution	n in Sample	
Age, mean (SD)	57.14	14.28	
<b>Gender,</b> <i>n</i> (%)			
Male	95	38.5	
Female	152	61.5	
Education level, mean (SD)	11.76	2.92	
Nationality, n (%)			
Dutch	243	98.4	
Different	4	1.6	
<b>Payed employment,</b> $n$ (%)			
Yes	58	23.5	
No	189	76.5	
<b>Living situation,</b> $n(\%)$			
Living alone	95	38.5	
Living together	152	61.5	
Somatic comorbidity, n (%)			
No comorbidity	129	52.2	
One or more comorbidity	118	47.8	
Vision status, n (%)			
Low vision	171	69.2	
Blind	76	30.8	
<b>Disease development,</b> $n$ (%)			
Stable	71	28.7	
Progressive	176	71.3	

Table 1 Demographic Data of Research Sample (N=247)

#### Materials

The invitation letter included an informed consent and an information letter about the study. Within the survey study, the patients had to complete different questionnaires. The questionnaires which were necessary to answer the formulated research questions above were the Fatigue Assessment Scale (FAS), the Modified Fatigue Impact Scale (MFIS), the Tenacious Goal Pursuit / Flexible Goal Adjustment Scale (TGPFGA), the Goal Adjustment Scale (GAS) and the Low Vision Quality of Life questionnaire (LVQoL). For all mentioned scales, Dutch versions were used and therefore the example items are also given in Dutch.

The Fatigue Assessment Scale was developed by Michielsen, De Vries, Van Heck, Van de Vijver and Sijtsma (2003) and is a 10-item unidimensional questionnaire with a 5point rating scale that varies from 1=nooit to 5=altijd. A sum score of maximum 50 points can be reached. A high score indicates severe fatigue. It was developed to measure the severity of fatigue. Example items are *Ik heb last van vermoeidheid* or *Ik heb geen zin om iets te ondernemen*. Michielsen et al. (2003) found in their study, which was aimed at determining the psychometric qualities of the FAS, a Cronbach's alpha of .90. Further the factor analysis confirmed that there is one factor that explains 67% of the variance. Within the present study a Cronbach's alpha of .82 was found.

The Modified Fatigue Impact Scale (MFIS), which was developed in 1998 by the Multiple Sclerosis Council for Clinical Practice Guidelines, is a 21-item questionnaire and psychometric analyses showed that it has three subscales, namely the cognitive-, the physical-, and the psychosocial subscale (Kos, Kerckhofs, Carrea, Verza, Ramos, & Jansa, 2005). It is a shortened version of the 40-item Fatigue Impact Scale and was therefore recommended for usage in clinical research to determine the impact of fatigue on daily life. A high score means a high impact of fatigue on daily life. Ratings vary from 1=nooit to 5=bijna altijd and example items for the physical subscale (sum score maximum 36) are Omwille van mijn vermoeidheid (gedurende de laatste 4 weken) voelden mijn spieren zwak aan or Omwille van mijn vermoeidheid (gedurende de laatste 4 weken) heb ik mijn fysieke activiteiten beperkt. For the cognitive subscale (sum score maximum 40), an example item is Omwille van mijn vermoeidheid (gedurende de laatste 4 weken) is mijn gedachtengang vertraagd geweest. The psychosocial subscale (sum score maximum 8) includes two items, namely Omwille van mijn vermoeidheid (gedurende de laatste 4 weken) ben ik minder gemotiveerd geweest om aan sociale activiteiten deel te nemen and Omwille van mijn vermoeidheid (gedurende de laatste 4 weken) ben ik beperkt geweest in de mogelijkheden buitenshuis. Kos et al. found the following Cronbach's alphas: .92 for the cognitive subscale, .88 for the physical subscale and .65 for the psychosocial subscale in 2005. Within the present study, the Cronbach's alpha were .92, .90 and .77. Thus, the Cronbach's alpha for the psychosocial subscale was even higher than in the study of Kos et al. in 2005.

The Tenacious Goal Pursuit Scale (TGP) respectively the Flexible Goal Adjustment Scale (FGA) were developed in 1990 by Brandstädter and Renner and measure the assimilative respectively the accommodative mode of the Brandtstädter model (Coffey, Gallagher, Desmond, & Ryall, 2014). Both scales consist of 15 items that could be answered via a five-point Likert scale that ranged from 1=geheel mee oneens to 5=geheel mee eens. The maximum sum score for the TGP and the FGA is 75. A high score means a that the patients make use of the strategies. An example item for the TGP is *Hoe moeilijker een doel te bereiken is, hoe aantrekkelijker ik het vind*. In contrast, one example item of the FGA is

*Wanneer ik ergens op vastloop, vind ik het moeilijk een andere aanpak te kiezen.* In past studies, the validity and reliability of both scales was observed to be satisfying. For instance, in the study of Coffey et al. (2014) Cronbach's alphas of .81 (TGP) and .64 (FGA) were found. In the present study, the TGP had a Cronbach's alpha of .74 and the FGA of .75. Thus, despite the fact that for the TGP a lower but still satisfying Cronbach's alpha was found, the Cronbach's alpha for the FGA was shown to be higher than in past studies.

The Goal Disengagement - and Goal Reengagement Scales are subscales of the Goal Adjustment Scale and consist of four respectively six items (Wrosch, Scheier, Miller, Schulz, & Carver, 2003). A high score indicates a high usage of the two strategies. An item of the Goal Disengagement Scale (sum score maximum 20) is Ik verlaag gemakkelijk mijn inspanningen om het doel te bereiken and for the Goal Reengagament Scale (sum score maximum 30), one item sounds as follows Ik overtuig mezelf ervan dat ik andere belangrijke doelen heb om na te streven. Patients could chose to give an answer from 1=Geheel mee oneens to 5=Geheel mee eens. Within the described cross-sectional study of Arends et al. (2013), the two subscales had a Cronbach's alpha from .53 and .88. However, in the present study the Cronbach's alpha was higher for the Goal Disengagement Subscale, namely .63 and .85 for the Goal Reengagement Subscale. The Low Vision Quality of Life Scale (possible sum score 126), developed in 2000 by Wolffsohn and Cochrane, has four different subscales, namely one for distance vision and mobility, one for adjustment, one for reading and fine work and one for activities of daily living (De Boer, Moll, De Vet, Terwee, Völker-Dieben, & Van Rens, 2004). A high score indicates lower vision-related quality of life. For the subscale distance vision and morbidity a sum score of 60 can be reached, whereas for the following two subscales a sum score of 24 is possible and for the subscale activities and daily living a maximum of 18 can be reached. One example item for the distance vision subscale is Hoeveel problemen heeft u met uw gezichtsvermogen s'avonds of s'nachts binnenshuis? Patients could chose to give an answer from 1=geen to 5=veel or 6=kan ik niet meer. A literature review from De Boer, Moll, De Vet, Terwee, Völker-Dieben and Van Rens (2004) showed that validity and reliability for the scales are properly. The reliability usually lays between .60 to .80. Within the present study, Cronbach's alpha of .81, .62, .92 and .62 were observed.

#### Procedure

Due to the visual impairment, an individual telephone interview was held with all patients wherein the interviewer read the questionnaires and filled in the answers that were given by the patients. Moreover, all patients were asked the same order of questionnaires. The interviewer started with questions about demographics, followed by questions about the eye-

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disease. After that, the questionnaires about fatigue, the LVQoL and the questionnaires about the coping strategies followed. The procedure took in average 90 minutes whereas the longest interviews took two hours and the shortest around an hour. After 45 minutes or at half of the questions, the patients were asked whether they want to have a short break.

## Data analysis

All the following quantitative analyses were conducted with the 22<sup>nd</sup> version of the statistical software programme SPSS. First of all, the overall sum scores of the six described questionnaires and the sum scores of the subscales were determined. For all studied variables, means and standard deviations were calculated. In addition, correlational analyses for all variables (demographics, goal-management strategies, low-vision related quality of life and the severity of fatigue and impact of fatigue) were conducted. For the ten percent missing values in the LVQoL, a multiple imputation with a predictive mean analysis was conducted with vision status as predictor variables. There were no missing values in the other questionnaires. For the hierarchical regressions, a check for normal distribution of the residuals was made with a linear regression analysis and a Q-Q plot. This plot indicated that the residuals are normally distributed. Outliers were studied with the Mahalanobis-distance. No outliers were excluded since the Mahalanobis-distance values and a created bar chart showed no need for it. It was checked for multicollinearity with the help of the variance proportions and there could not be seen multicollinearity among the different predictors. Furthermore, four separate hierarchical multiple regression analyses were conducted with severity of fatigue respectively impact of fatigue as dependent variable. The first model within the hierarchical regression included the demographic variables that showed a significant correlation with the mentioned dependent variables. In the second model, the variable vision related quality of life respectively the four goal management strategies were added. For fatigue severity the demographics gender, education, work and comorbidity were included because these variables showed a significant correlation with the dependent variable. For impact of fatigue as dependent variable, gender, education and comorbidity were added due to the significant correlations.

#### Results

#### **Preliminary Analyses**

The means and standard deviations are shown in table 2. The mean of fatigue severity was higher in comparison to the sample of Michielsen et al. (2003) who researched among workers and found a mean of 19.26 (SD=6.52). For the impact of fatigue, Kos et al. (2006)

who researched the qualities of the MFIS among people who suffered from MS, found a mean which was higher (M=43). In the sample of the present study, the mean of the vision-related quality of life was not remarkable different than within the sample of De Boer et al. in 2004 who also researched among visually impaired people. This was also the case for the means of the goal management strategies because within the sample of Arends et al. (2013) comparable means could be found. As already noted within the method section, the Cronbach's alphas of the questionnaires were satisfying. Nevertheless, the goal disengagement scale had the lowest Cronbach's alpha in comparison to the other goal-management strategy scales.

Variable	Mean	Standard Deviation	Cronbach's alpha
Fatigue severity	23.22	6.37	.82
Fatigue impact	31.40	16.71	.95
Goal adjustment	54.36	8.56	.75
Goal Pursuit	49.38	8.44	.74
Goal reengagement	23.74	4.23	.85
Goal disengagement	11.12	3.32	.63
Vision related quality of life	69.84	16.78	.81

Table 2 Means and Standard Deviations for the dependent - and independent Variables

## Correlations

The found correlations are shown in table 3. In fact, the dependent variable of fatigue severity had significant relations with the demographics gender, education, work and comorbidity. Gender, work and comorbidity were positively related to fatigue severity. Education which was expressed in years was negatively related. Moreover, all four goal-management strategies are significantly negative related to fatigue severity. Regarding the impact of fatigue, comorbidity, education and gender were significantly related. As with fatigue severity, comorbidity and gender were positively related whereas education level was negatively related to the impact of fatigue. In addition to this, the goal-management strategies were significantly negative related as well. With regard to vision-related quality of life, it has to be mentioned that this variable is significantly positive related to severity as well as to the impact of fatigue. Despite the significant correlations, the relations were low in general. In fact, one moderate correlation was between goal adjustment and goal reengagement.

15																		1	
14																	1	.32**	
13																1	.07*	09**	
12															1	06*	<u>.</u> 05	**60	
11														-	<u>-</u> .05	.22**	.22**	02	
10													1	28**	.08**	13**	08**	01	
6												1	17**	.35**	.10**	.20**	-02	03	
~											1	03	14**	01	10	.12**	08**	.08**	
6									1		.11**	10**	*90	04	0	01	.02	.08**	
9							1		.18**		11.	.08**	11**	**60	.01	-02	02	07**	
S						1	20**		.15**		01	13**	07	**60	12**	-0	.08**	-06*	
4					1	.38**	.28**		.43**		.13**	.07**	06*	.12**	07**	90.	9	00'-	
3			1		.01	*90'	12**		04*		04	.13**	.16**	25**	**60.	02	11**	.52**	
2		-	.34**		15**	11**	07**		07**		.16**	6	07**	02	03	.17**	0.	01	
1		.75**	.28**		24**	21**	17**		05*		.10**	03	15**	.08**	02	.15**	<u>6</u>	02	
Variable	<ol> <li>Fatigue severity</li> </ol>	2.Fatigue impact	<ol><li>Low vision</li></ol>	quality of life	4.Goal adjustment	5.Goal pursuit	6.Goal	disengagement	7.Goal	reengagement	8.Gender	9.Age	10.Education	11.Work	12.Living situation	13.Comorbidity	14. Vision status	15.Time since	diagnosis

Table 3 Pearson Correlations for studied Variables

Note. Gender. 1=male, 2=female; Work. 1=yes, 2=no; Living situation. 0=alone, 1=living together; Comorbidity. 0=none, 1=one or more; Vision status. 1=low vision, 2=blind. \*\*Correlation is significant at the 0.01 level (2-tailed). \*. Correlation is significant at the 0.05 level (2-tailed).

## Multiple hierarchical regression analyses

As described in the data analysis, the goal management strategies and the vision-related quality of life served as independent variables. In order to have a look how the several independent variables contribute to the two dependent variables (fatigue severity and fatigue impact), the independent variables were put block wisely into models to conduct four separate hierarchical regression analyses (see table 4 and table 5). In fact, four hierarchical regressions were conducted because the goal-management strategies and the vision-related quality of life were put into two separate models. The reason is that the strategies are a psychological concept and the latter variable displays a more physical concept that needed to be distinguished in the analyses.

Variable	Fatigue severity	Fatigue impact
	ß	ß
Demographic variables		
$\Delta R^2$	.046***	.048***
Gender	.069**	.131***
Education	123***	035
Comorbidity	.126***	.149***
Work	.013	
Goal management strategies		
$\Delta R^2$	.090***	.035***
Goal adjustment	183***	132***
Goal pursuit	131***	069*
Goal disengagement	026	049
Goal reengagement	069**	006
$R^2$ total	.135***	.083***

Table 4	Results	Hierarchica	l Regres	sion for	Goal M	anagement	Model
10000	10000000	III CI CI CINCO	1105100	Stongor	00000 111		11100000

Note.

\*p<.05. \*\*p<.01. \*\*\*p<.001

Table 5	Results	Hierarchical	Regression	for	Quality o	f Life Model
			0	2	~ ~ ~	/ /

Variable	Fatigue severity	Fatigue impact
Demographic variables	1.7	15
$\Delta R^2$	.046***	.040***
Gender	.086**	.142***
Education	117***	031
Comorbidity	.133***	.113***
Work	003	-
Vision related quality of life		
$\Delta R^2$	.054***	.098***
	.243***	.326***
$R^2$ total	.101***	.138***

Note.

\*p<.05. \*\*p<.01. \*\*\*p<.001

Due to the two formulated research questions from the introduction, the results for fatigue severity and fatigue impact are described separate from each other. The coefficients of the demographics that are presented in the two tables above are the coefficients before adding the goal-management strategies respectively the vision-related quality of life variables into the models.

#### **Fatigue severity**

The included demographics explained nearly 5% of the variance for fatigue severity (see table 4). Every demographic variable except of working situation was a highly significant predictor. In fact, the goal-management strategies added 9% variance explanation to the model. The strategies of goal adjustment, goal pursuit and goal reengagement were the significant predictors. The goal disengagement strategy was not a significant predictor. With regard to the first research question, all goal-management strategies except of goal disengagement act as a contributor to fatigue severity in visually impaired people (research question 1).

When looking at the second hierarchical regression which included the vision-related quality of life, the demographics explained more than 4% of the variance and the vision-related quality of life variable added nearly 5% as a significant predictor (see table 5). Vision related quality of life also acts as a contributor to fatigue severity in visually impaired people (research question 2).

#### **Fatigue impact**

For fatigue impact, the demographics also explained nearly 5% of the variance (see table 4). Only gender and number of comorbidities were significant predictors in this model. The goalmanagement strategies added more than 3%, whereas goal adjustment and goal pursuit were the only significant predictors. Thus, regarding the first research question, the two goalmanagement strategies goal adjustment and goal pursuit acted as a contributor to the impact of fatigue in visually impaired people (research question 1). Figure 3 visualises a linear regression for the strongest predictor goal adjustment and the dependent variable fatigue impact to give an impression to the reader how the distribution within the sample was.

With regard to the vision-related quality of life (final model), the demographics explained 4%. As already shown in the hierarchical regression analysis with the goalmanagement strategies, gender and number of comorbidities are the only significant predictors. In addition to this, the low-vision quality of life variable added nearly 10% explanation in variance to the model and was a highly significant predictor (see table 5). This

confirms the role of vision related quality of life in impact of fatigue for visually impaired people (research question 2).



FIGURE 3 The role of the goal adjustment strategy in the impact of fatigue. (SSMFIS=sum score of the MFIS). (SSFGA= sum score of the FGA)

In general one can say that within the present study all four models explained a low amount of variance of the two dependent variables.

## Discussion

The formulated research questions of this study were: *Do the goal-management strategies* (*goal-maintenance, goal-adjustment, goal-disengagement and goal-reengagement*) act as a *contributor to the perceived fatigue severity and perceived impact of fatigue in visually impaired people?* (Research question one) and: *What is the role of vision-related quality of life in the perceived fatigue severity and perceived impact of fatigue in visually impaired people?* (Research question two). The findings revealed that not all four goal-management strategies contributed to fatigue severity respectively fatigue impact. In fact, goal disengagement was not related to fatigue severity and goal disengagement and goal reengagement were both not related to fatigue impact. The vision-related quality of life indeed contributed to both dependent fatigue variables. Lower vision-related quality of life was related to more severe fatigue and more impact of fatigue on daily life.

With regard to the formulated research questions, previous research let to the hypotheses that the goal-management strategies are negatively related to fatigue severity as well as to the perceived impact of fatigue because fatigue is described as a subjective concept that can be overcome with help of the individual's coping strategies (Hewlett et al., 2011). Within this present study, the correlational results showed that this was indeed the case for

both dependent fatigue variables although the relations were not strong in general. The hierarchical regression analyses showed a relationship of goal adjustment and goal pursuit to fatigue severity as well as to impact of fatigue for visually impaired people. This is in concordance with results from previous studies for people with acquired brain injury (Brands, Stapert, Köhler, Wade, & van Heugten, 2015). It is not surprising that especially the goal adjustment strategy was related to less fatigue because shifting the attention to the attainable goals and the adjustment of goals was already proven to be successful in reducing for example depression among visually impaired people (Garnefski, Kraaij, De Graaf, & Karels, 2010).

However, the results of the hierarchical regressions also pointed out that not all four goal-management strategies played a role within the concept of fatigue severity respectively the impact of fatigue. From the study of Boerner and Wang (2012), it was hypothesised that especially the goal-management strategies that belong to the accommodative mode (goal adjustment, -disengagement and reengagement) were expected to decrease the dependent fatigue variables in visually impaired people. However, the use of the goal disengagement strategy was not related to less severe fatigue. This was also applicable for the impact of fatigue with the additional fact that goal reengagement was also not a significant contributor. As a consequence, one could ask why the disengagement respectively disengagement and reengagement (see the impact of fatigue) were not related to less fatigue like the goal adjustment strategy, although the study from Arends et al. (2013) emphasised that all these three strategies are seen as interrelated parallel processes within the accommodative mode. For Arends et al. (2013) who had a similar outcome regarding goal disengagement, this was explained by a possible shared variance of goal adjustment and goal disengagement due to the moderate relation between these two strategies. As stated, within the present study goal reengagement in place of goal disengagement and goal adjustment had the strongest relation in comparison to other variables although this relation was only moderate. Thus, this could also suggest a shared variance due to an interrelated parallel process. Despite this fact, past literature from Neter, Litvak and Miller (2009) indicated that there could be found significant relations between goal dis - and goal reengagement and depression among patients who suffer from MS. Less use of goal disengagement and goal reengagement led to less depression. People who made use of goal disengagement without reengaging into new goals, were more affected by depression. Thus, there could also be found an interdependence between goal disengagement and goal reengagement. It is known that depression and fatigue are related to each other (Jaremka et al., 2014). In addition to this, the positive input of goal reengagement could also be found for depressed visually impaired people within the study of Garnefski,

Kraaij, De Graaf and Karels 2010. Therefore, the question remains why there could not be found a relation between goal disengagement respectively goal reengagement and fatigue within the present study. It is possible that the Cronbach's alpha for the goal disengagement scale in comparison to the Cronbach's alphas for the other goal management strategies gives the impression that the measurement of this coping strategy could be improved. Moreover, the stated research examples from literature show that the goal-management scales were mainly used to identify relations to other concepts like pain, depression or adaption and not always to fatigue directly. Thus, the questionnaires might not be optimal for usage when trying to identify the relations with fatigue. However, one should be careful with this sort of conclusions. Nevertheless, the outcome within the present study emphasises once again the statement from Wrosch et al. (2003) within the introduction that said to conduct further studies with the focus on the usefulness of disengagement from personal goals because the role of variables like motivation, effort and control - also in combination with goal reengagement - are difficult to determine.

When looking at the vision related quality of life, this variable also acted as a contributor to fatigue severity respectively the impact of fatigue within this sample (research question two). Thus, less vision-related quality of life was related to more fatigue severity and more impact of fatigue on daily life. This is in concordance with the hypothesis that was mentioned in the introduction. This hypothesis stated that the severity of an eye-condition has a negative impact on the quality of life which in consequence can contribute to more fatigue (Chia, Wang, Rochtchina, Smith, Cumming, & Mitchell, 2004) Thus, besides the psychological concept of goal-management, the physical concept of the limitations that are caused by the eye-disease also play a role when it comes to fatigue. Nevertheless, there was an amount of items that were not answered regarding the LVQoL scale. When looking at these items, it seems like some patients were not aware or unsure about the physical limitations they have. Increasing patient's awareness of own physical restrictions and in consequence instructing them how to cope with these could be related to the feeling of fatigue as well but this statement is a suggestion that is in need of future research.

Moreover, the low proportion of variance that the goal-management strategies as well as the vision-related quality of life explained in both fatigue variables within this sample is important to stress. This leads to the suggestion that other variables play a role when it comes to fatigue in visually impaired people that were not measured within the present study like for instance engagement in sport activities. It was already stressed in the introduction that visually impaired people have difficulties to be physically active due to the restrictions and

limitations they experience because of the eye-diseases (Asplund, 2000). For example, Alma, Van der Mei, Melis-Dankers, Van Tilburg, Groothoff and Suurmeijer (2011) found that elderly who suffer from visual impairment often engage in less sport activities compared to other elderly without a visual impairment. Motl, McAuley, Snook and Gliottoni (2009) reported that physical activity and sport can reduce fatigue and in consequence improve the quality of life for people with MS. Therefore, physical activity and sport activity could be possible variables to integrate into future research regarding fatigue among visual impaired people.

Furthermore, one of the demographic variables that were included in the hierarchical regression models due to the significant correlations with the dependent variables was gender. Moreover, this variable showed to be a highly significant predictor of fatigue severity as well as to the impact of fatigue. In fact, women reported more severe fatigue and more impact of fatigue on daily life in comparison to men. The study of Asplund from 2000 also indicated that women report fatigue more often than men. Although the relation of gender and fatigue was weak within the present study, the question that rises is: Where do these gender related differences regarding fatigue come from? Research by Bensing, Hulsman and Schreurs (1999) already emphasised that gender-specific biology factors like menstruation and menopause could be a reason for the found differences among men and women. Moreover, a double load due to work and taking care of a family or children influences women more negatively when it comes to perceived fatigue than it influences men. However, working situation was not a significant predictor within the present study but this could be explained by the fact that within this special sample of visually impaired people only 58 even had a paid employment. Nevertheless, these outcomes indicate that gender differences with regard to fatigue severity as well as to fatigue impact can be found even among visually impaired people and there is a need to explore the origin of these differences in future research.

General positive aspects of the present study are the conditions under which the study was conducted. Although the questionnaires were not filled in by the participants themselves but by interviewers who asked the different items via the phone, the reliability of all questionnaires was equal to previous studies in other populations. Moreover, all questionnaires are used for a long time in research and have proven validity and reliability. The visual impairment obviously did not cause any problems regarding the measurement of the different variables. Moreover, the different results for fatigue severity and the impact of fatigue confirm that these concepts have to be seen separate from each other to get a whole overview on this concept as it was already pointed out by previous research. This is a next

step into the direction of understanding and exploring the complexity of fatigue.

In contrast, one limitation of this study is the cross-sectional conduction because no conclusions about causality can be formulated. Thus, it would be informative to conduct a longitudinal study to get an impression whether the results would change over long term or not because Brandtstädter and Rothermund (2002) stressed that nowadays life is unstable and uncertain over time. A second limitation is the high distribution of the different eye-diseases within the sample. One should be careful with drawing similar conclusions for the different eye-disease because people could cope differently depending on which eye-disease they have due to individual or situational factors (Bonanno & Burton, 2013).

Therefore, besides already noted suggestions for further research, another practical implication for further studies is to use a sample wherein the participants suffer from the same eye-disease. In addition to this, further research should focus more on the found gender differences. Although the relationship between gender and fatigue was rather weak, past research indicated that these differences were found more often and this could suggest another structure of rehabilitation programme to treat fatigue in women in comparison to men. However, for this reason these differences and the effect of these should be determined beforehand.

#### Conclusion

In the introduction, it was stated that the experience of fatigue is a common issue among people who suffer from a visual impairment. The described study stressed that some facts about fatigue in samples with long term conditions that were already researched and reported in literature can also be found among a sample that consists of visually impaired people like the positive role of goal-management. Nevertheless, the vision-related quality of life also plays a role in fatigue and this is an important fact because it stresses that besides psychological concepts like goal-management also physical limitations that are caused by an eye-disease are related to fatigue. However, it has to be mentioned that despite significant results the relations were weak in general. Therefore, one should focus on adding more variables that could explain fatigue among visually impaired people as it was mentioned in the discussion. Moreover, the role of the goal-management strategies regarding fatigue should be subject of future research to explore especially the role of goal disengagement and goal reengagement further, so that these self-management strategies can be thematised in rehabilitation programmes as well.

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