

VU Research Portal

Measuring participation in children and young adults with visual impairment: the development of instruments

Elsman-Perlot, E.B.M.

2020

document version

Publisher's PDF, also known as Version of record

[Link to publication in VU Research Portal](#)

citation for published version (APA)

Elsman-Perlot, E. B. M. (2020). *Measuring participation in children and young adults with visual impairment: the development of instruments*. [PhD-Thesis - Research and graduation internal, Vrije Universiteit Amsterdam].

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

E-mail address:

vuresearchportal.ub@vu.nl

Chapter 4

**Quality of life and participation of young adults with
visual impairment aged 18-25 years: comparison
with population norms**

EBM Elsman, GHMB van Rens & RMA van Nispen

Acta Ophthalmologica, 2019; 97(2):165-172

Abstract

Purpose

To compare health-related quality of life and participation of visually impaired young adults with normative groups, and to explore severity of vision loss and its association with participation and quality of life.

Methods

Young adults aged 18-25 years (n=172) registered at two Dutch low vision rehabilitation organisations completed the Short Form Health Survey (SF-36), EuroQol-5 Dimensions (EQ-5D), Impact on Participation and Autonomy (IPA), and Low Vision Quality of Life questionnaire (LVQOL). EQ-5D and SF-36 scores were compared to age-specific norms. IPA scores were compared to norms of a population having three chronic diseases simultaneously. Linear regression was used to assess the association between severity of vision loss (mild VI, moderate VI and severe VI/blindness), and quality of life and participation.

Results

Participants scored significantly worse on almost all (sub)scales compared with relevant norms. Effect sizes for the EQ-5D and SF-36 (sub)scales were mostly small; moderate and large effect sizes were found for the IPA. Compared to young adults with mild VI, corrected models showed a significant association between having moderate VI and the physical component score of the SF-36, and between severe VI/blindness and the LVQOL.

Conclusion

VI has a moderate impact on some aspects of quality of life and a large impact on participation of young adults when compared with relevant normative populations. Severity of vision loss is associated with worse physical functioning and vision-related quality of life. The results contribute to a better understanding of the impact of VI and might lead to improved low vision services.

Introduction

Although prevalence of visual impairment (VI) increases with older age, estimates of VI among younger adults should not be overlooked.¹ Since many eye conditions are irreversible and progressive, VI in early adulthood may have lifelong implications. Having a (visual) impairment may affect a young adult's transition to adulthood,²⁻⁴ which might result in psychological distress,⁵ and interference with developmental tasks,⁶ such as study, employment and housing.⁷⁻¹⁰

Subjective evaluation of a person's health status is recognised as an important strategy in the evaluation of treatment of visually impaired persons.¹¹⁻¹⁴ In many studies quality of life and functioning has been investigated in various populations with VI (e.g. ¹⁵⁻¹⁷), often specifically focusing on older adults because of the higher prevalence of VI. In contrast, there are fewer studies in which quality of life in children and adolescents with VI is discussed,¹⁸⁻²¹ probably due to low prevalence and difficulty to collect sufficient data. To evaluate quality of life and participation in populations with VI, both generic (e.g. ^{22,23}) and vision-related health questionnaires (e.g. ^{24,25}) can be used. The latter are valuable for assessing vision-related problems and are more sensitive to vision-related functioning.²⁶⁻²⁹

The quality of life of older adults with VI is significantly worse than that of the general population,^{16,30} and similar results have been found for children and adolescents.^{20,21} Qualitative data show that young adults with VI often experience problems related to employment and education, whereas also social life, leisure-time activities and mobility are important topics to be addressed.^{4,31} However, to the best of our knowledge, no studies have compared quality of life and participation in young adults with VI with data from the general population.

Therefore, to gain insight into young adults with VI, this study aims to: i) compare their participation levels and health-related quality of life with reported comparison groups, and ii) explore the severity of vision loss and its association with participation and quality of life.

Methods

Participants and procedure

Data for this study was collected as part of a validation study of a new questionnaire, i.e. the Participation and Activity Inventory for Young Adults (PAI-YA). Young adults aged 18-25 years who at that time were or had previously been enrolled for care at two Dutch low vision rehabilitation centres were invited to participate.

Because of low prevalence of VI and large variations in ophthalmic conditions in this particular age group, young adults with low vision from any cause were eligible to participate; there was no restriction regarding visual performance. Those who agreed to participate completed the Dutch versions of the Short Form Health Survey (SF-36), EuroQoL-5 Dimensions (EQ-5D), Low Vision Quality of Life questionnaire (LVQOL), Impact on Participation and Autonomy (IPA), and a

questionnaire assessing sociodemographic and clinical characteristics. Young adults had the option to complete the questionnaires through a web-based survey questionnaire, a paper-and-pencil version, a telephone interview, or via a face-to-face interview (home visit).

The study protocol was approved by the Medical Ethical Committee of the VU University Medical Centre, Amsterdam, the Netherlands. The study adhered to the tenets of the Declaration of Helsinki (and its later amendments). Written informed consent was obtained from all participants.

Measurements

Health-related quality of life

Health-related quality of life was assessed using the Dutch versions of the SF-36³² and EQ-5D, which are generic instruments.^{33,34} Both instruments are commonly used across a range of populations and diseases, including ophthalmic conditions and in visually impaired populations.^{15-17,27-30,35} The SF-36 consists of 36 items that measures eight scales: physical functioning (PF-10 items), role limitations due to physical problems (RP-4 items), bodily pain (BP-2 items), general perception of health (GH-5 items), social functioning (SF-2 items), role limitations due to emotional functioning (RE-3 items), vitality (VT-4 items), and mental health (MH-5 items). Items on each scale were summed and rescaled to a score from 0-100, with higher values representing better quality of life. Furthermore, the physical and mental component scores (PCS and MCS, respectively) were calculated using Dutch age-specific norm scores (mean=50; SD=10).³² The EQ-5D consists of five questions covering mobility, self-care, usual activities, pain/discomfort, and depression/anxiety. Each question is scored on five levels, allowing to describe 3125 (5⁵) unique health states. To each health state a utility score can be assigned by applying scores from preference weights, so called tariffs. Utility scores based on the Dutch tariff were calculated,^{36,37} where 0 corresponds to death and 1 to a state of perfect health.

Vision-related quality of life

Vision-related quality of life was measured with the LVQOL.²⁵ The previously validated 18-item unidimensional version was used, in which items are scored on a 6-point Likert scale. Because of floor effects, the response options 5 and 6 were collapsed.³⁸ A score was calculated ranging from 0-72, with higher values representing better vision-related quality of life.

Participation

To investigate the impact of VI on participation, the IPA was used,³⁹ consisting of 32 items scored on a 5-point Likert scale which can be assigned to five scales: autonomy indoors (AI-7 items), family role (FR-7 items), autonomy outdoors (AO-5 items), social life and relationships (SR-7 items), and work and education (WO-6 items). A score was calculated for each scale ranging from 0-20/24/28, depending on the number of items. Lower values represent better perceived autonomy and participation.

Sociodemographic and clinical characteristics

Participants were asked about a number of sociodemographic and clinical characteristics, including age, gender, educational level, financial situation, and comorbidity. Decimal visual acuity, visual field and ophthalmic diagnoses were retrieved from patient files at low vision rehabilitation centres. Missing values were supplemented by self-reported data of participants ($n=1$ for diagnosis, $n=3$ for visual acuity). Visual acuity was converted into logMAR, and put into 3 levels based on the better seeing eye, according to WHO categories of VI.⁴⁰ Mild VI referred to $\log\text{MAR} \leq 0.52$, moderate VI to $\log\text{MAR} > 0.52 \leq 1$, and severe VI/blindness to $\log\text{MAR} > 1$. When data on visual field were available, visual field of ≤ 10 degrees was classified as severe VI/blindness; otherwise, visual acuity was used for classification.

Statistical analyses

All analyses were performed using SPSS version 22.0. Descriptive statistics were used to describe sociodemographic and clinical characteristics of participants. Cronbach's alpha was calculated for each (sub)scale to evaluate internal consistency reliability. Scores of participants on (sub)scales of the SF-36, EQ-5D and IPA were compared to norm scores found in literature using one-sample *t*-tests. For the SF-36 and EQ-5D, scores of participants were compared to age-specific (16-40 years and 20-24 years respectively) norm scores of the general Dutch population.^{32,36} Participants' IPA scores were compared to norm scores retrieved from the National Panel Chronic Illness and Disability in which persons with chronic somatic illnesses and/or sensory or motor disabilities are represented.⁴¹ Participants' scores were compared to the worse norm scores available, i.e. norms of a population having three chronic diseases simultaneously.⁴² Clinical significance of the differences were evaluated using Cohen's effect sizes, where 0.20-0.49 are considered small, 0.50-0.79 moderate and ≥ 0.80 large.⁴³

To explore the role of vision loss severity on participation and quality of life, as expressed by scores of the (sub)scales, linear regression analyses were performed. The assumptions of normality, linearity and multicollinearity were checked. Because some distributions of dependent variables were skewed, log transformation was performed on the SF-36 psychological component scores, and the IPA 'autonomy indoors' and 'family role' scores. Regression coefficients and confidence intervals resulting from these analyses were back-transformed and therefore represent ratios. First, linear regression analyses were performed to investigate the association between severity of VI and (sub)scales of the SF-36, EQ-5D, LVQOL and IPA; mild VI served as reference. Subsequently, the same association was investigated and corrected for age, gender, financial situation, comorbidity, and level of education.

Results

Of all invited young adults, 218 (20.1%) gave written informed consent to participate in the study. Of those, 172 filled in the SF-36, 171 the EQ-5D, 170 the IPA, and 164 filled in the LVQOL. However, a summary score for 111 participants could be computed for the 'work and education' subscale of

the IPA due to missing values, because participants had no paid/voluntary work. Characteristics of the participants are shown in Table 1. A large variety of ophthalmic conditions and causes for VI were reported (over 50), of which albinism (11.1%), retinitis pigmentosa (10.0%), congenital nystagmus (6.3%) and optic atrophy (5.8%) were most common as a primary cause. Most participants had VI since birth (64.5%). Almost half of the participants (40.7%) reported to have some type of comorbidity.

Table 1. Sociodemographic and clinical characteristics of participants (n=172)

Participant characteristic	
Age in years, mean \pm SD (range)	21.39 \pm 2.25 (18-25)
Male gender, n (%)	79 (45.9)
Category of VI ^a , n (%)	
Severe VI/blindness: logMAR >1 or visual field \leq 10 degrees	35 (20.4)
Moderate VI: logMAR >0.52 \leq 1	61 (35.5)
Mild VI: logMAR \leq 0.52	75 (43.6)
Unknown	1 (0.6)
Time of VI onset birth, n (%)	111 (64.5)
Diagnosis by site of VI ^b , n (%)	
Whole globe and anterior segment	3 (1.7)
Glaucoma	3 (1.7)
Cornea (sclerocornea and corneal opacities)	7 (4.1)
Lens (cataract and aphakia)	7 (4.1)
Uvea	4 (2.3)
Retina	75 (43.6)
Optic nerve	21 (12.2)
Cerebral/visual pathways	24 (14.0)
Other (nystagmus, high refractive error)	28 (16.3)
Education, n (%)	
Primary	8 (4.7)
Secondary	131 (76.2)
Higher	19 (11.0)
Unknown	14 (8.1)
Method of completion, n (%)	
Online	151 (87.8)
Telephone interview	18 (10.5)
Paper-and-pencil version	3 (1.7)
Face-to-face, n (%)	0 (0.0)
Dutch nationality, n (%)	158 (91.1)
Currently studying, n (%)	110 (64.0)
Currently having a paid (part-time) job, n (%)	63 (36.6)
Currently doing voluntary work, n (%)	41 (23.8)
Financial situation, n (%)	
Usually enough money	87 (50.6)
Just enough money	48 (27.9)
Not enough money	10 (5.8)
No answer	27 (15.7)
Comorbidity, n (%)	70 (40.7)
Cognitive impairment, n (%)	9 (5.2)

a World Health Organisation categories of visual impairment based on acuity in better seeing eye/visual field⁴⁰

b Primary cause of visual impairment was used for classification

Internal consistency for all (sub)scales was good, with Cronbach's alpha of >0.7 (SF-36 subscales: 0.77-0.91; EQ-5D: 0.74; LVQOL: 0.90; IPA subscales: 0.83-0.92). Table 2 presents scores of participants for (sub)scales of the SF-36, EQ-5D and IPA compared to norm scores in the literature. Participants had significantly lower (i.e. worse) scores on all subscales (except for 'bodily pain') of the SF-36. Effect sizes were mostly small, but moderate effect sizes were found for 'role limitations due to physical problems' and 'vitality'. Participants scored significantly lower (i.e. worse) on the EQ-5D than the general Dutch population, but the effect size was small. Participants scored higher (i.e. worse) on all IPA subscales than persons having three simultaneous chronic diseases, and all results were significant except for 'autonomy indoors'. However, the participants' score on this scale was significantly worse when compared to the norm score for the general population with one or two chronic diseases simultaneously ($p=0.004$ and $p=0.032$, respectively; data not shown). Moderate effect sizes were found for 'family role', whereas large effect sizes were found for 'autonomy outdoors', 'social life and relationships', and 'work and education'.

Table 2. Comparison of participants' scores with norm data from the literature^{32,36,44}

(sub)scale ^a	n	Score, mean (SD)	Normative data	T Statistic	p-value	Effect size
SF-36 PF	172	88.9 (19.1)	93.1	-2.89	0.004	0.26
SF-36 RP	172	67.4 (36.8)	86.4	-6.76	<0.001	0.58
SF-36 RE	172	76.4 (36.9)	85.4	-3.22	0.002	0.27
SF-36 SF	172	79.2 (21.7)	87.8	-5.18	<0.001	0.42
SF-36 BP	172	83.4 (20.7)	80.9	1.59	0.114	-0.12
SF-36 MH	172	70.4 (18.7)	78.7	-5.83	<0.001	0.49
SF-36 VT	172	59.2 (19.5)	70.7	-7.74	<0.001	0.64
SF-36 GH	172	68.8 (22.8)	78.2	-5.41	<0.001	0.46
SF-36 PCS	172	46.7 (12.1)	50.0	-3.53	0.001	0.30
SF-36 MCS	172	44.8 (12.5)	50.0	-5.47	<0.001	0.46
EQ-5D	171	0.86 (0.19)	0.90	-2.98	0.003	0.23
IPA AI	170	2.48 (3.47)	2.1	1.42	0.159	-0.15
IPA FR	170	5.51 (5.43)	2.7	6.74	<0.001	-0.72
IPA AO	170	5.05 (4.18)	2.6	7.63	<0.001	-0.81
IPA SR	170	5.85 (3.99)	2.2	11.94	<0.001	-1.28
IPA WO	111	6.65 (5.02)	2.8	8.08	<0.001	-1.06

^a SF-36 and EQ-5D: higher scores represent better quality of life (SF-36 compared to general population aged 16-40 years; EQ5D 20-24 years); IPA: lower scores represent better participation (compared to persons with 3 chronic diseases). PF=physical functioning, RP=role limitations due to physical problems, RE=role limitations due to emotional functioning, SF=social functioning, BP=bodily pain, MH=mental health, VT=vitality, GH=general health, PCS=physical component score, MCS=mental component score, AI=autonomy indoors, FR=family role, AO=autonomy outdoors, SR=social life and relationships and WO=work and education.

Except for the LVQOL questionnaire and the physical component scale of the SF-36, no significant trends were observed related to severity of vision loss and any of the (sub)scales of the other outcomes (Table 3). The uncorrected model shows that moderate VI was significantly associated with worse scores on the physical component scale of the SF-36 as compared to mild VI, and severe VI/blindness was significantly associated with worse scores on the LVQOL compared with mild VI. After correcting for potential confounders, these associations remained.

Table 3. Association between severity of vision loss (moderate VI or severe VI/blindness) and the SF-36, EQ-5D, IPA and LVQOL (sub)scales as compared to a reference group with mild VI

Dependent variable ^a	Uncorrected model: β (95% CI)			Corrected model: β (95% CI) ^b		
	n	Severe VI/blindness ^c	Moderate VI ^c	n	Severe VI/blindness ^c	Moderate VI ^c
SF-36 PCS ^d	171	0.95 (0.75, 1.20)	0.80 (0.66, 0.98)	136	0.92 (0.71, 1.18)	0.81 (0.65, 1.00)
SF-36 MCS	171	-1.70 (-6.77, 3.38)	-0.20 (-4.47, 4.08)	136	-2.10 (-7.48, 3.28)	0.36 (-4.11, 4.84)
EQ-5D	170	0.03 (-0.05, 0.11)	0.01 (-0.06, 0.08)	136	-0.01 (-0.08, 0.07)	-0.01 (-0.07, 0.06)
IPA AI ^d	169	1.02 (0.70, 1.48)	0.80 (0.59, 1.09)	135	1.00 (0.65, 1.54)	0.75 (0.52, 1.07)
IPA FR ^d	169	1.36 (0.90, 2.04)	0.94 (0.67, 1.32)	135	1.42 (0.90, 2.24)	0.89 (0.61, 1.30)
IPA AO	169	1.13 (-0.57, 2.84)	-0.51 (-1.94, 0.91)	135	1.01 (-0.73, 2.76)	-0.82 (-2.27, 0.64)
IPA SR	169	1.08 (-0.55, 2.70)	-0.70 (-2.05, 0.66)	135	0.74 (-1.11, 2.59)	-0.69 (-2.23, 0.86)
IPA WO	111	1.43 (-1.40, 4.25)	-0.55 (-2.62, 1.52)	93	2.12 (-0.71, 4.95)	-0.90 (-2.92, 1.13)
LVQOL	163	-10.34 (-15.99, -4.69)	-2.65 (-7.29, 1.99)	129	-11.44 (-17.43, -5.45)	-4.07 (-8.99, 0.85)

^a SF-36, EQ-5D and LVQOL: higher scores represent better quality of life; IPA: lower scores represent better participation. PCS=physical component score, MCS=mental component score, AI=autonomy indoors, FR=family role, AO=autonomy outdoors, SR=social life and relationships and WO=work and education.

^b Corrected for age, gender, financial situation, comorbidity and level of education.

^c Severe VI/blindness: logMAR >1 or visual field ≤ 10 degrees, Moderate VI: logMAR >0.52 ≤ 1 , Mild VI: logMAR ≤ 0.52 ; ⁴⁰ Mild VI served as reference.

^d Log transformation was performed, regression coefficients and confidence intervals were back-transformed and represent ratios.

Bold is significant at $p < 0.05$.

Discussion

This study reports on quality of life and participation of young adults aged 18-25 years with VI, as assessed with the SF-36, EQ-5D, LVQOL and IPA. Furthermore, this study provides insight into health and vision-related quality of life and participation of young adults with VI and its association with severity of vision loss.

With respect to health-related quality of life, young adults scored significantly worse on the EQ-5D and on all scales of the SF-36 when compared with age-specific norms, except for 'bodily pain'. Earlier studies also found that patients with low vision experienced less pain than comparison populations.^{16,27} The results were often of high statistical significance, indicating an effect, even though the magnitude of the effect is small as indicated by the small effect sizes, which might suggest limited clinical relevance. Moderate effect sizes were found for 'role limitations due to physical problems' and 'vitality'. This extends findings of other studies showing that having VI affects various aspects related to participation (including activities related to work, study and daily activities),⁴ and that greater impairment of vision or having irreversible VI is associated with increased fatigue.^{15,45}

Regarding participation, young adults scored significantly worse on all IPA subscales (except for 'autonomy indoors') when compared with a population having three simultaneous chronic conditions. The finding that 'autonomy indoors' was perceived to be less problematic could be due to the content of the items (i.e. five items focused on self-care, which is more often reported not to be affected by VI^{16,46}) or because young adults' houses are adapted to their VI. Moreover, young adults are familiar with their home environment, whereas the outdoor environment might be less familiar and less predictable. A moderate effect size was found for 'family role', indicating that young adults with VI experience more problems with their role, tasks and responsibilities within their family or household than a population having three chronic diseases simultaneously. Large effect sizes were found for 'autonomy outdoors', 'social life and relationships', and 'work and education', indicating that young adults with VI perceive less autonomy and more problems on these aspects than a population having three chronic diseases simultaneously, echoing the results of a concept-mapping study.⁴ Although topics related to mobility, work, and education are often prevalent in the discussion of needs of young adults at for example low vision rehabilitation centers,³¹ topics related to social life and relationships are often overlooked.^{31,47} However, a large number of studies show that young adults with VI experience difficulties with social, intimate and romantic relationships (e.g. ^{4,9,48-51}). This study now quantitatively shows that young adults indeed do experience more problems related to social life and relationships compared to a population having three chronic diseases simultaneously, and that these topics should be emphasised when offering low vision rehabilitation services to young adults. Because social participation in young adults with VI is still diminished, available programmes in low vision rehabilitation centres appear not to be sufficient. A recent study to the effectiveness of a mentoring programme to improve social participation and psychosocial functioning for youth with VI aged 15 to 22 years found only

limited positive effects on psychosocial functioning.⁵² A systematic review towards the effectiveness of interventions to improve quality of life and participation in children and adolescents with VI also found few studies with limited effectiveness.⁵³ Therefore, more work is necessary to experimentally evaluate programmes aimed at improving social participation outcomes in youth and young adults with VI.

Some of the results of this study differ from the results of other studies where the same instrument was used in other populations.^{15-17,20,27,28,54} Mixed results were found in comparison with scores of young adults on the SF-36 to scores of older adults for most subscales.^{15,17,27,28,54} Young adults performed worse compared to some studies and better compared to others; differences were often not large. However, the study of Scott et al. showed a 62.4 point difference in the 'role limitations due to physical problems' subscale and a 70.8 point difference in the 'role limitations due to emotional problems' subscale, where their participants had worse quality of life on these domains compared to young adults.²⁷ In general, young adults had worse quality of life compared to the study of Tsai et al., in which Taiwanese older adults were included, except for the 'physical functioning' subscale.¹⁷ Young adults rated their physical functioning better compared to all other studies, which is probably due to confounding by age; participants in other studies had a mean age of at least 69 years old.^{15,17,27,28,54} On the other hand, young adults perceived their mental health as worse compared to older adults. On the 'social functioning' subscale of the SF-36, young adults often scored worse compared to older adults; only the older participants in the study of Chia et al. performed worse on social functioning.¹⁵ This finding adds additional weight to the suggestion that low vision rehabilitation services should give special attention to social life and relationships when providing services to young adults. Young adults with VI in the current study performed better on the EQ-5D compared to participants in the study of Langelaan et al., in which working age adults were included (mean age 42 years) and the same questionnaire was used.¹⁶ Furthermore, young adults rated their vision-related quality of life only slightly worse compared to a proxy measure for children in the study of Chadha et al. (scores were transformed in a 0-100 scale because different versions of the LVQOL were used in both studies).²⁰ No studies could be identified in which the IPA was used in a population with VI. In general it thus seems that young adults with VI perceive their mental health as worse and also perform worse on social functioning than older adults, whereas they perform better with respect to physical functioning. Results for other domains are less straightforward. In future, it might be interesting to investigate whether different age groups perceive their quality of life and participation differently.

The finding that effect sizes of the IPA are larger than effect sizes of the SF-36 and EQ-5D could indicate that quality of life of young adults with VI is comparable with that of sighted peers, whereas their participation is considerably less. However, another explanation is that the IPA might be more sensitive to the impact of VI than generic health-related quality of life questionnaires such as the SF-36 and EQ-5D. It is well known from previous literature that vision-related instruments are more sensitive to the effects of VI than generic instruments. Although Macedo et al. found that the EQ-5D was useful for characterizing the burden of VI,⁵⁵ Malkin et al.

found that the EQ-5D was not responsive to changes induced by low vision rehabilitation.⁵⁶ As they pointed out, the EQ-5D is not very specific, and at least one of the five domains (i.e. pain/discomfort) is often not affected by VI. The study of Parrish et al. found that the SF-36 was only weakly correlated with impairment in visual acuity or visual field,²⁸ and also others have stated that generic instruments are probably less sensitive to ocular conditions than vision-related health outcome measures.^{26,27,29} Although the IPA is a generic instrument as well, it was developed for use in patients with various chronic health conditions, and has been validated in a population with chronic health conditions as well, i.e. having somatic illnesses and/or sensory or motor disabilities.^{39,57} It measures participation as reflected in the International Classification of Functioning, Disability and Health (ICF)⁵⁸ and combines this with autonomy, in order to add a personal dimension to the concept of participation.^{39,57} As such, the IPA can be used to quantify limitations in participation and autonomy. It might be the autonomy part that is interwoven in the items of the IPA (e.g. my contribution to tasks in and around the house *as I want to...*; the possibility to spend my (leisure) time *as I want to...*) makes it more sensitive to the personal experience of participants, and thereby more sensitive to the effects of VI. The questionnaires in this study were completed as part of the validation study of the PAI-YA, a new questionnaire to assess the participation levels of young adults with a visual impairment, and identify their needs. The PAI-YA was developed with young adults with VI and professionals from multidisciplinary rehabilitation services.⁴ Advanced analyses provided evidence for its robust psychometric properties, including validity and reliability.⁵⁹

Our results show variation in quality of life and participation within the group of young adults with VI, and no clear trend between worse scores with more severe vision loss could be observed, except for the LVQOL, a result more often found in studies involving older adults.²⁶⁻²⁹ After correcting for potential confounders, a significant association remained between moderate VI and the physical component scale of the SF-36, and between severe VI/blindness and the LVQOL, as compared to young adults with mild VI. However, the percentage of variance explained was low and, therefore, other factors (e.g. perceived health status or acceptance of vision loss)⁶⁰ are also likely to play a role. The absence of a clear trend and the low explained variance might also be caused by the first limitation of our study, which is possible misclassification of participants into categories of VI due to incomplete patient files. For example, visual field was often not measured or objectively reported in patient files at low vision rehabilitation centres. Instead, more subjective terms as 'peripheral field loss superior', 'left-sided hemianopia' or 'strong concentrically restricted' were used. It could be that some participants are thus misclassified into categories of VI due to incomplete visual field data, and may have more severe VI than the chosen category of VI suggests. Therefore, it might be that we underestimate the impact of the severity of vision loss on quality of life.

Although we anticipated a low response rate based on experiences from previous research involving the same target population, this can be considered a second limitation.⁴ This might have been caused by limitations in the accessibility and user-friendliness of the study information (a

letter was sent to all eligible participants) or questionnaires. Despite tailored questionnaire administration modes were offered, young adults were unlikely to choose the administration mode requiring researchers' assistance (i.e. only 10.5% chose a telephone interview and nobody chose a face-to-face interview). The life stage of young adults is characterised by the transition of becoming an adults, with a growing need for independence and autonomy,⁶¹ asking for assistance could therefore be at odds. Nevertheless, the low response rate might indicate selection bias and might affect generalisability of the results.

The study population was very diverse, as they had a large variety of ophthalmic conditions and causes of VI (over 50 different causes were identified from patient files). Furthermore, there were no restrictions regarding visual performance, which has resulted in large variations in visual acuity and visual field of participants. Furthermore, over 40% of the participants reported to have some type of comorbidity, which might have affected quality of life and participation as well. The diversity of the study participants might have caused the large number of small effect sizes.⁶² Diverse study populations can lead to large standard deviations, which in turn have an influence on the effect sizes. Alternatively, there might be a truly small difference in quality of life and participation scores of young adults with VI compared to relevant population norms. However, most effect sizes were between 0.40 and 0.50, i.e. at the higher end of the small effect size range. Moreover, according to Cohen, even a small effect size is not so small that it should be considered trivial or unimportant.⁴³

In addition, the EQ-5D scores were negatively skewed, and logarithmic and square root transformations did not result in a normal distribution. Therefore, the untransformed scores were used as the dependent variables. This might have affected the estimates of the standard error and, consequently, the confidence interval around our estimates.⁶³

A strength of this study is the use of psychometrically sound instruments. The SF-36 and EQ-5D have been widely used in various populations, including those with ophthalmic conditions.^{15-17,26-30,35} Moreover, the IPA was developed and validated in the Netherlands, and has adequate psychometric properties.³⁹ For the LVQOL, the 18-item validated version was used.³⁸ In the present study, internal consistency reliability for all (sub)scales was sufficient, contributing to the validity of the instruments.

Another strength is the use of effect sizes to represent the magnitude of the effect in terms of units of standard deviation. Effect sizes are independent of sample size and are, therefore, considered to contribute to the assessment of clinical significance or meaningfulness of the results.⁶⁴ For the SF-36, the approach of using effect sizes differs from the perspective of the developers, who suggested a benchmark of at least 20 points as being clinically significant.⁶⁵ We saw differences around 10 points between participants' scores and norm scores from literature, with the largest difference found for 'role limitations due to physical problems' (-19.0 points compared to norms).

In conclusion, this study shows that quality of life of young adults with VI is only moderately affected regarding some aspects compared to the general population, while their participation is considerably worse. After correcting for potential confounders, having moderate VI was associated with worse physical functioning when compared with young adults with mild VI. Moreover, young adults with severe VI or blindness experienced worse vision-related quality of life when compared with their counterparts with mild VI. The results of this study contribute to a better understanding of the quality of life and participation of young adults with VI. Using this information, changes might be made in programmes offered by low vision services allowing better support of young adults with VI. Focus should be placed on those aspects where large effect sizes were found (i.e. autonomy outdoors, work and education, and social life and relationships).

Acknowledgement

We greatly thank all participating young adults. A grant for this study was provided by the Association of Institutions for People with a Visual Impairment (VIVIS).

References

1. Bourne RRA, Flaxman SR, Braithwaite T, Cicinelli MV, Das A, Jonas JB, . . . Vision Loss Expert G. Magnitude, temporal trends, and projections of the global prevalence of blindness and distance and near vision impairment: a systematic review and meta-analysis. *Lancet Glob Health*. 2017; 5(9):e888-e897
2. Huurre TM, Aro HM. Psychosocial development among adolescents with visual impairment. *European Child & Adolescent Psychiatry*. 1998; 7(2):73-78
3. Stewart D, Freeman M, Law M, Healy H, Burke-Gaffney J, Forhan M, . . . Guenther S: Transition to adulthood for youth with disabilities: evidence from literature, in Stone JH, Blouin M (eds): *International Encyclopedia of Rehabilitation*, 2010
4. Elsmann EBM, Van Rens GHMB, Van Nispen RMA. Impact of visual impairment on the lives of young adults in the Netherlands: a concept-mapping approach. *Disability and Rehabilitation*. 2016; 39(26):2607-2618
5. Rous B, Hallam R, Harbin G, McCormick K, Jung LA. The transition process for young children with disabilities - A conceptual framework. *Infants and Young Children*. 2007; 20(2):135-148
6. Boerner K, Wang SW, Cimarolli VR. The impact of functional loss: Nature and implications of life changes. *Journal of Loss & Trauma*. 2006; 11(4):265-287
7. Nurmi JE. Age-Differences in Adult Life Goals, Concerns, and Their Temporal Extension - a Life Course Approach to Future-Oriented Motivation. *International Journal of Behavioral Development*. 1992; 15(4):487-508
8. Wehman P: *Life beyond the classroom: transition strategies for young people with disabilities*. Baltimore, Brookes Publishing Co., 2006
9. Sacks SZ, Wolfe KE: *Teaching social skills to students with visual impairments: research to practice*. New York, AFB Press, 2006
10. Kef S, Dekovic M. The role of parental and peer support in adolescents well-being: a comparison of adolescents with and without a visual impairment. *Journal of Adolescence*. 2004; 27(4):453-466
11. de Boer MR, Moll AC, de Vet HC, Terwee CB, Volker-Dieben HJ, van Rens GH. Psychometric properties of vision-related quality of life questionnaires: a systematic review. *Ophthalmic Physiol Opt*. 2004; 24(4):257-273
12. Margolis MK, Coyne K, Kennedy-Martin T, Baker T, Schein O, Revicki DA. Vision-specific instruments for the assessment of health-related quality of life and visual functioning: a literature review. *Pharmacoeconomics*. 2002; 20(12):791-812
13. Massof RW, Rubin GS. Visual function assessment questionnaires. *Surv Ophthalmol*. 2001; 45(6):531-548
14. Gill TM, Feinstein AR. A critical appraisal of the quality of quality-of-life measurements. *JAMA*. 1994; 272(8):619-626
15. Chia EM, Wang JJ, Rochtchina E, Smith W, Cumming RR, Mitchell P. Impact of bilateral visual impairment on health-related quality of life: the Blue Mountains Eye Study. *Invest Ophthalmol Vis Sci*. 2004; 45(1):71-76
16. Langelaan M, de Boer MR, van Nispen RM, Wouters B, Moll AC, van Rens GH. Impact of visual impairment on quality of life: a comparison with quality of life in the general population and with other chronic conditions. *Ophthalmic Epidemiol*. 2007; 14(3):119-126
17. Tsai SY, Chi LY, Cheng CY, Hsu WM, Liu JH, Chou P. The impact of visual impairment and use of eye services on health-related quality of life among the elderly in Taiwan: the Shihpai Eye Study. *Qual Life Res*. 2004; 13(8):1415-1424
18. Chak M, Rahi JS, British Congenital Cataract Interest G. The health-related quality of life of children with congenital cataract: findings of the British Congenital Cataract Study. *Br J Ophthalmol*. 2007; 91(7):922-926
19. Boulton M, Haines L, Smyth D, Fielder A. Health-related quality of life of children with vision impairment or blindness. *Dev Med Child Neurol*. 2006; 48(8):656-661
20. Chadha RK, Subramanian A. The effect of visual impairment on quality of life of children aged 3-16 years. *Br J Ophthalmol*. 2011; 95(5):642-645
21. Wong HB, Machin D, Tan SB, Wong TY, Saw SM. Visual impairment and its impact on health-related quality of life in adolescents. *Am J Ophthalmol*. 2009; 147(3):505-511 e501
22. Ware JE, Jr., Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care*. 1992; 30(6):473-483
23. Brooks R. EuroQol: the current state of play. *Health Policy*. 1996; 37(1):53-72

24. Steinberg EP, Tielsch JM, Schein OD, Javitt JC, Sharkey P, Cassard SD, . . . et al. The VF-14. An index of functional impairment in patients with cataract. *Arch Ophthalmol*. 1994; 112(5):630-638
25. Wolffsohn JS, Cochrane AL. Design of the low vision quality-of-life questionnaire (LVQOL) and measuring the outcome of low-vision rehabilitation. *Am J Ophthalmol*. 2000; 130(6):793-802
26. Mangione CM, Phillips RS, Lawrence MG, Seddon JM, Orav EJ, Goldman L. Improved visual function and attenuation of declines in health-related quality of life after cataract extraction. *Arch Ophthalmol*. 1994; 112(11):1419-1425
27. Scott IU, Smiddy WE, Schiffman J, Feuer WJ, Pappas CJ. Quality of life of low-vision patients and the impact of low-vision services. *Am J Ophthalmol*. 1999; 128(1):54-62
28. Parrish RK, 2nd, Gedde SJ, Scott IU, Feuer WJ, Schiffman JC, Mangione CM, Montenegro-Piniella A. Visual function and quality of life among patients with glaucoma. *Arch Ophthalmol*. 1997; 115(11):1447-1455
29. Schiffman RM, Jacobsen G, Whitcup SM. Visual functioning and general health status in patients with uveitis. *Arch Ophthalmol*. 2001; 119(6):841-849
30. Polack S, Kuper H, Wadud Z, Fletcher A, Foster A. Quality of life and visual impairment from cataract in Satkhira district, Bangladesh. *Br J Ophthalmol*. 2008; 92(8):1026-1030
31. Van Leeuwen LM, Rainey L, Kef S, Van Rens GHMB, Van Nispen RMA. Investigating rehabilitation needs of visually impaired young adults according to the International Classification of Functioning, Disability and Health. *Acta Ophthalmologica*. 2015; 93(7):642-650
32. Aaronson NK, Muller M, Cohen PD, Essink-Bot ML, Fekkes M, Sanderman R, . . . Verrips E. Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. *J Clin Epidemiol*. 1998; 51(11):1055-1068
33. Herdman M, Gudex C, Lloyd A, Janssen M, Kind P, Parkin D, . . . Badia X. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Qual Life Res*. 2011; 20(10):1727-1736
34. Janssen MF, Pickard AS, Golicki D, Gudex C, Niewada M, Scalone L, . . . Busschbach J. Measurement properties of the EQ-5D-5L compared to the EQ-5D-3L across eight patient groups: a multi-country study. *Qual Life Res*. 2013; 22(7):1717-1727
35. Polack S, Kuper H, Mathenge W, Fletcher A, Foster A. Cataract visual impairment and quality of life in a Kenyan population. *Br J Ophthalmol*. 2007; 91(7):927-932
36. Stolk E, Krabbe P, Busschbach J. Using the internet to collect EQ-5D norm scores: a valid alternative? 24th Scientific Plenary Meeting of the EuroQol Group. 2009:153-164
37. Versteegh MM, Vermeulen KM, Evers SMAA, de Wit GA, Prenger R, Stolk EA. Dutch Tariff for the Five-Level Version of EQ-5D. *Value in Health*. 2016; 19(4):343-352
38. Van der Aa HP, van Rens GH, Comijs HC, Margrain TH, Gallindo-Garre F, Twisk JW, van Nispen RM. Stepped care for depression and anxiety in visually impaired older adults: multicentre randomised controlled trial. *BMJ*. 2015; 351:h6127
39. Cardol M, de Haan RJ, van den Bos GA, de Jong BA, de Groot IJ. The development of a handicap assessment questionnaire: the Impact on Participation and Autonomy (IPA). *Clin Rehabil*. 1999; 13(5):411-419
40. WHO: International Statistical Classification of Diseases and Related Health Problems 10th Revision. Version 2010. Chapter VII, H54: Visual impairment including blindness. Geneva, World Health Organization, 2010
41. Nivel: National Panel Chronic Illness and Disability [Nationaal Panel Chronisch Zieken en Gehandicapt], Nivel, 2017
42. Meetinstrumenten: Impact op Participatie en Autonomie (Impact on Participation and Autonomy), Vol. 2017, Meetinstrumenten in de Zorg (Measurement Instruments in Health Care), 2013
43. Cohen J. Statistical power analysis for the behavioural sciences. Hillsdale, New Jersey, Lawrence Earlbaum Associates, 1988
44. Van Engelen E. Detailed explanation of the measurement instrument Impact on Participation and Autonomy (IPA) [Uitgebreide toelichting van het meetinstrument Impact op Participatie en Autonomie (IPA)], Vol. 2017, Measurement instruments in healthcare [Meetinstrumenten in de zorg], 2013
45. Mojon-Azzi SM, Sousa-Poza A, Mojon DS. Impact of low vision on well-being in 10 European countries. *Ophthalmologica*. 2008; 222(3):205-212

46. Massof RW, Hsu CT, Baker FH, Barnett GD, Park WL, Deremeik JT, . . . Epstein C. Visual disability variables. I: the importance and difficulty of activity goals for a sample of low-vision patients. *Arch Phys Med Rehabil.* 2005; 86(5):946-953
47. Boerner K, Cimarolli VR. Optimizing rehabilitation for adults with visual impairment: attention to life goals and their links to well-being. *Clinical Rehabilitation.* 2005; 19(7):790-798
48. Kef S, Hox JJ, Habekothte HT. Social networks of visually impaired and blind adolescents. Structure and effect on well-being. *Social Networks.* 2000; 22(1):73-91
49. Kroksmark U, Nordell K. Adolescence: The age of opportunities and obstacles for students with low vision in Sweden. *Journal of Visual Impairment & Blindness.* 2001; 95(4):213-225
50. Kef S, Bos H. Is love blind? Sexual behavior and psychological adjustment of adolescents with blindness. *Sexuality and Disability.* 2006; 24(2):89-100
51. Gold D, Shaw A, Wolffe K. The Social Lives of Canadian Youths with Visual Impairments. *Journal of Visual Impairment & Blindness.* 2010; 104(7):431-443
52. Heppe ECM: Social participation of adolescents with a visual impairment: social support, mentoring and psychosocial functioning. Amsterdam, Vrije Universiteit Amsterdam, 2018
53. Elsman EBM, Al Baaj M, Van Rens GHMB, Sijbrandi W, Van den Broek EGC, Van der Aa HPA, . . . Van Nispen RMA: Interventions to improve participation and quality of life in children with visual impairment: a systematic review. *Survey of Ophthalmology.* 2019; 64(4):512-557
54. Wilson MR, Coleman AL, Yu F, Bing EG, Sasaki IF, Berlin K, . . . Lai A. Functional status and well-being in patients with glaucoma as measured by the Medical Outcomes Study Short Form-36 questionnaire. *Ophthalmology.* 1998; 105(11):2112-2116
55. Macedo AF, Ramos PL, Hernandez-Moreno L, Cima J, Baptista AMG, Marques AP, . . . Santana R. Visual and health outcomes, measured with the activity inventory and the EQ-5D, in visual impairment. *Acta Ophthalmologica.* 2017; 95(8):e783-e791
56. Malkin AC, Goldstein JE, Perlmutter MS, Massof RW, Low Vision Research Network Study G. Responsiveness of the EQ-5D to the effects of low vision rehabilitation. *Optom Vis Sci.* 2013; 90(8):799-805
57. Cardol M: Questionnaire 'Impact on Participation and Autonomy' (IPA) - user manual [Vragenlijst 'Impact op Participatie en Autonomie' (IPA) - handleiding], 2005
58. WHO: The International Classification of Functioning, Disability and Health: ICF. Geneva, 2001
59. Elsman EBM, Van Rens GHMB, Van Nispen RMA: Psychometric properties of a new intake questionnaire for visually impaired young adults: the Participation and Activity Inventory for Young Adults (PAI-YA). *Plos One.* 2018; 13(8): e0201701
60. Van der Aa HP, Xie J, Rees G, Fenwick E, Holloway EE, van Rens GH, van Nispen RM. Validated Prediction Model of Depression in Visually Impaired Older Adults. *Ophthalmology.* 2016; 123(5):1164-1166
61. Arnett JJ: Emerging adulthood: the winding road from the late teens through the early twenties. Oxford, England, Oxford University Press, 2004
62. Sullivan GM, Feinn R. Using Effect Size-or Why the P Value Is Not Enough. *J Grad Med Educ.* 2012; 4(3):279-282
63. Li X, Wong W, Lamoureux EL, Wong TY. Are linear regression techniques appropriate for analysis when the dependent (outcome) variable is not normally distributed? *Invest Ophthalmol Vis Sci.* 2012; 53(6):3082-3083
64. Fan XT. Statistical significance and effect size in education research: Two sides of a coin. *Journal of Educational Research.* 2001; 94(5):275-282
65. McHorney CA, Ware JE, Jr., Raczek AE. The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. *Med Care.* 1993; 31(3):247-263

