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

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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 organizations 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.**

Key words: participation – quality of life – visual impairment – young adults

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Introduction

Although prevalence of visual impairment (VI) increases with older age, estimates of VI among younger adults should not be overlooked (Bourne et al. 2017). As 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 (Huurre & Aro 1998; Stewart et al. 2010; Elsman et al. 2016), which might result in psychological distress (Rous et al. 2007), and interference with developmental tasks (Boerner et al. 2006), such as study, employment and housing (Nurmi 1992; Kef & Dekovic 2004; Sacks & Wolffe 2006; Wehman 2006).

Subjective evaluation of a person's health status is recognized as an important strategy in the evaluation of treatment of visually impaired persons (Gill & Feinstein 1994; Massof & Rubin 2001; Margolis et al. 2002; de Boer et al. 2004). In many studies, quality of life and functioning have been investigated in various populations with VI (e.g. Chia et al. 2004; Tsai et al. 2004; Langelaan et al. 2007), 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 (Boulton et al. 2006; Chak & Rahi 2007; Wong et al. 2009; Chadha & Subramanian 2011), 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. (Ware & Sherbourne 1992; Brooks 1996)) and vision-related health questionnaires (e.g. Steinberg

et al. 1994; Wolffsohn & Cochrane 2000) can be used. The latter are valuable for assessing vision-related problems and are more sensitive to vision-related functioning (Mangione et al. 1994; Parrish et al. 1997; Scott et al. 1999; Schiffman et al. 2001).

The quality of life of older adults with VI is significantly worse than that of the general population (Langelaan et al. 2007; Polack et al. 2008), and similar results have been found for children and adolescents (Wong et al. 2009; Chadha & Subramanian 2011). 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 (Van Leeuwen et al. 2015; Elsman et al. 2016). 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: (1) compare their participation levels and health-related quality of life with reported comparison groups, and (2) explore the severity of vision loss and its association with participation and quality of life.

Materials and Methods

Participants and procedure

Data for this study were collected as part of a validation study of a new questionnaire, that is the Participation and Activity Inventory for Young Adults (PAI-YA) (Elsman et al. 2018). 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 Center, 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-36 (Aaronson et al. 1998) and EQ-5D, which are generic instruments (Herdman et al. 2011; Janssen et al. 2013). Both instruments are commonly used across a range of populations and diseases, including ophthalmic conditions and in visually impaired populations (Parrish et al. 1997; Scott et al. 1999; Schiffman et al. 2001; Chia et al. 2004; Tsai et al. 2004; Langelaan et al. 2007; Polack et al. 2007, 2008). The SF-36 consists of 36 items that measure 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 to 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; Aaronson et al. 1998). 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 (5^5) 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 (Stolk et al. 2009; Versteegh et al. 2016), 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 (Wolffsohn & Cochrane 2000). 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 (van der Aa et al. 2015). A score was calculated ranging from 0 to 72, with higher values representing better vision-related quality of life.

Participation

To investigate the impact of VI on participation, the IPA was used (Cardol et al. 1999), 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 to 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 puts into 3 levels based on the better-seeing eye, according to WHO categories of VI (WHO 2010). Mild VI referred to logMAR ≤ 0.52, moderate VI to logMAR >0.52 ≤ 1 and severe VI/blindness to logMAR >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 (IBM Corp 2013). 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 (Aaronson et al. 1998; Stolk et al. 2009). 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 (Nivel 2017). Participants' scores were compared to the worse norm scores available, that is norms of a population having three chronic diseases simultaneously (Meetinstrumenten 2013). Clinical significance of the differences was evaluated using Cohen's effect sizes, where 0.20–0.49 are considered small, 0.50–0.79 moderate and ≥0.80 large (Cohen 1988).

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 psychical 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 was 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.

Internal consistency for all (sub) scales was good, with Cronbach's alpha >0.7 (SF-36 subscales: 0.77–0.91; EQ-5D: 0.74; LVQOL: 0.90; and 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'.

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.

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 (Scott et al. 1999; Langelaan et al. 2007). 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; Elsman et al. 2016), and that greater impairment of vision or having irreversible VI is associated with increased fatigue (Chia et al. 2004; Mojon-Azzi et al. 2008).

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 (Massof et al. 2005; Langelaan et al. 2007)) 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 (Elsman et al. 2016). 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 centres (Van Leeuwen et al. 2015), topics related to social life and relationships are often overlooked (Boerner & Cimarolli 2005; Van Leeuwen et al. 2015). However, a large number of studies show that young adults with VI experience difficulties with social, intimate and romantic relationships (e.g. Kef et al. 2000; Kroksmark & Nordell 2001; Kef & Bos 2006; Sacks & Wolffe 2006; Gold et al. 2010; Elsman et al. 2016). 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 emphasized 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 15–22 years found only limited positive effects on psychosocial functioning (Heppe 2018). 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 (E.B.M. Elsman, M. Al Baaj M, G.H.M.B. Van Rens, unpublished data). 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 (Parrish et al. 1997; Wilson et al. 1998; Scott et al. 1999; Chia et al. 2004; Tsai et al. 2004; Langelaan et al. 2007; Chadha & Subramanian 2011). Mixed results were found in comparison with scores of young adults on the SF-36 to scores of older adults for most subscales (Parrish et al. 1997; Wilson et al. 1998; Scott et al. 1999; Chia et al. 2004; Tsai et al. 2004). 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 (Scott et al. 1999). In general, young adults had worse quality of life compared to the study of Tsai et al. (2004), in which Taiwanese older adults were included, except for the 'physical functioning' subscale. Young adults rated their physical functioning better compared to all other studies, which is probably due to confounding by age;

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

Participant characteristic	
Age in years, mean ± SD (range)	21.39 ± 2.25 (18–25)
Male gender, *n* (%)	79 (45.9)
Category of VI*	
Severe VI/blindness: logMAR >1 or visual field ≤10 degrees, *n* (%)	35 (20.4)
Moderate VI: logMAR >0.52 ≤1, *n* (%)	61 (35.5)
Mild VI: logMAR ≤0.52, *n* (%)	75 (43.6)
Unknown, *n* (%)	1 (0.6)
Time of VI onset birth, *n* (%)	111 (64.5)
Diagnosis by site of VI†	
Whole globe and anterior segment, *n* (%)	3 (1.7)
Glaucoma, *n* (%)	3 (1.7)
Cornea (sclerocornea and corneal opacities), *n* (%)	7 (4.1)
Lens (cataract and aphakia), *n* (%)	7 (4.1)
Uvea, *n* (%)	4 (2.3)
Retina, *n* (%)	75 (43.6)
Optic nerve, *n* (%)	21 (12.2)
Cerebral/visual pathways, *n* (%)	24 (14.0)
Other (nystagmus, high refractive error), *n* (%)	28 (16.3)
Education	
Primary, *n* (%)	8 (4.7)
Secondary, *n* (%)	131 (76.2)
Higher, *n* (%)	19 (11.0)
Unknown, *n* (%)	14 (8.1)
Method of completion	
Online, *n* (%)	151 (87.8)
Telephone interview, *n* (%)	18 (10.5)
Paper-and-pencil version, *n* (%)	3 (1.7)
Face-to-face, *n* (%)	0 (0.0)
Nationality	
Dutch, *n* (%)	158 (91.9)
Other, *n* (%)	14 (8.1)
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	
Usually enough money, *n* (%)	87 (50.6)
Just enough money, *n* (%)	48 (27.9)
Not enough money, *n* (%)	10 (5.8)
No answer, *n* (%)	27 (15.7)
Comorbidity, *n* (%)	70 (40.7)
Cognitive impairment, *n* (%)	9 (5.2)

* World Health Organization categories of visual impairment based on acuity in better-seeing eye/visual field (WHO 2010).
† Primary cause of visual impairment was used for classification.

participants in other studies had a mean age of at least 69 years old (Parrish et al. 1997; Wilson et al. 1998; Scott et al. 1999; Chia et al. 2004; Tsai et al. 2004). 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. (2004) performed worse on social functioning. 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. (2007), in which working age adults were included (mean age 42 years) and the same questionnaire was used. 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 & Subramanian (2011) (scores were transformed in a 0–100 scale because different versions of the LVQOL were used in both studies). 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

Table 2. Comparison of participants' scores with norm data from the literature (Aaronson et al. 1998; Stolk et al. 2009; Van Engelen 2013).

(Sub)scale*	*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

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

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

	Uncorrected model: β (95% CI)			Corrected model†: β (95% CI)		
Dependent variable*	*n*	Severe VI/blindness‡	Moderate VI‡	*n*	Severe VI/blindness‡	Moderate VI‡
SF-36 PCS§	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§	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§	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)

AI = autonomy indoors; AO = autonomy outdoors; FR = family role; MCS = mental component score; PCS = physical component score; SR = social life and relationships; WO = work and education.
* SF-36, EQ-5D and LVQOL: higher scores represent better quality of life; IPA: lower scores represent better participation.
† Corrected for age, gender, financial situation, comorbidity and level of education.
‡ Severe VI/blindness: logMAR >1 or visual field ≤10 degrees, Moderate VI: logMAR >0.52 ≤1, Mild VI: logMAR ≤0.52 (WHO 2010); Mild VI served as reference.
§ Log transformation was performed, regression coefficients and confidence intervals were back-transformed and represent ratios.
Bold is significant at $p < 0.05$.

literature that vision-related instruments are more sensitive to the effects of VI than generic instruments. Although Macedo et al. (2017) found that the EQ-5D was useful for characterizing the burden of VI, Malkin et al. (2013) found that the EQ-5D was not responsive to changes induced by low vision rehabilitation. 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. (1997) found that the SF-36 was only weakly correlated with impairment in visual acuity or visual field, and also others have stated that generic instruments are probably less sensitive to ocular conditions than vision-related health outcome measures (Mangione et al. 1994; Scott et al. 1999; Schiffman et al. 2001). 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, that is having somatic illnesses and/or sensory or motor disabilities (Cardol et al. 1999; Cardol 2005). It measures participation as reflected in the International Classification of Functioning, Disability and Health (ICF; WHO 2001) and combines this with autonomy, in order to add a personal dimension to the concept of participation (Cardol et al. 1999; Cardol 2005). 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 (Elsman et al. 2016). Advanced analyses provided evidence for its robust psychometric properties, including validity and reliability (Elsman et al. 2018).

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 (Mangione et al. 1994; Parrish et al. 1997; Scott et al. 1999; Schiffman et al. 2001). 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 (van der Aa et al. 2016)) 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 (Elsman et al. 2016). 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 characterized by the transition of becoming an adult, with a growing need for independence and autonomy (Arnett 2004); asking for assistance could therefore be at odds. Nevertheless, the low response rate might indicate selection bias and might affect generalizability 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. Besides, 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 (Sullivan & Feinn 2012). 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, that is 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 (Cohen 1988).

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 (Li et al. 2012).

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 (Mangione et al. 1994; Parrish et al. 1997; Scott et al. 1999; Schiffman et al. 2001; Chia et al. 2004; Tsai et al. 2004; Langelaan et al. 2007; Polack et al. 2007, 2008). Moreover, the IPA was developed and validated in the Netherlands, and has adequate psychometric properties (Cardol et al. 1999). For the LVQOL, the 18-item IRT validated version was used (van der Aa et al. 2015). 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 (Fan 2001). 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 (McHorney et al. 1993). 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 were large effect sizes were found (i.e. autonomy outdoors, work and education, and social life and relationships).

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