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Strabismus is more than a misalignment; a cross-sectional pilot study of HRQOL in Finnish strabismic adults referred to a university hospital

Anna Mason^{1,2} | Laura Lindberg³ | Katja Joronen⁴ | Anna-Maija Koivisto¹ | Anja Rantanen¹

¹Health Sciences, Faculty of Social Sciences, Tampere University, Tampere, Finland

²Head and Neck Center, Helsinki University Hospital and University of Helsinki, Helsinki, Finland

³Department of Ophthalmology, Helsinki University Hospital and University of Helsinki, Helsinki, Finland

⁴Department of Nursing Science, University of Turku, Turku, Finland

Correspondence

Anna Mason, Health Sciences, Faculty of Social Sciences, Tampere University, Tampere, Finland; Head and Neck Center, Helsinki University Hospital and University of Helsinki, Helsinki, Finland. Email: anna.mason@hus.fi

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Abstract

Purpose: To evaluate associations between the health-related quality of life (HRQOL) and demographic, self-reported strabismus-related and orthoptic status variables in Finnish strabismic adults.

Methods: Participants (n=137) of this study were adult patients who previously participated in the pilot study to translate and validate Adult Strabismus Questionnaire (AS-20) into Finnish. For this study, the participants' orthoptic status were collected among the previously obtained self-reported demographic and strabismus-related data. The refined AS-20 structure of 18 items and four subscales of self-perception, interaction, reading function and general function was used. Low scores on AS-20 indicate low HRQOL. The associations were evaluated with cross-tabulation and nonparametric methods of Mann-Whitney U and Kruskal–Wallis tests. Statistical significance was set at p < 0.05. **Results:** Interaction subscale scores were the highest of all subscale scores among the participants. Age had an association with HRQOL in self-perception and the youngest participants had the lowest scores. Importantly, participants who did not experience diplopia suffered from lower self-perception and interaction but reported higher scores on reading function and general function subscales compared to the participants who experienced diplopia. Exotropia with or without vertical strabismus were most common types among the participants. The education background was not associated with HRQOL.

Conclusion: Impacts of strabismus are similar in Finnish strabismic adults compared to international studies. Healthcare professionals and decision-makers should always consider the psychosocial impact of strabismus on patients without diplopia when making decisions on strabismus treatment and care processes.

KEYWORDS

Adult Strabismus Questionnaire (AS-20), health-related quality of life, impacts of strabismus, strabismus

1 | INTRODUCTION

Strabismus, an ocular misalignment, affects 3%–4% the adult population (Hashemi et al., 2019; Marsh, 2015) and its impact is both on functional and psychosocial well-being (Adams et al., 2016; Buffenn, 2021; Chang et al., 2015; Hatt et al., 2007; McBain, MacKenzie,

et al., 2014). Individuals might struggle with their self-esteem, appearance-related issues, feelings of anxiety, inferiority and mental illnesses (Adams et al., 2016; Buffenn, 2021; McBain, Au, et al., 2014; Wang et al., 2018). Strabismus can cause adults to avoid social situations and interactions, thus having difficulties in interpersonal relationships or finding a life partner.

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Unfortunately, some have experiences of discrimination (Durnian et al., 2011; McBain et al., 2016; Wang et al., 2018). Binocularity difficulties such as diplopia cause functional struggles and affect individuals' everyday tasks for example driving, reading, working, watching TV or hobbies (Hatt et al., 2007; Wang et al., 2018). Adults with strabismus can struggle walking on stairs or uneven terrain (Hatt et al., 2007) and consequently have an increased risk of injury (Buffenn, 2021; Wang et al., 2018). Strabismus can also have an economic influence by impacting an individual's employment opportunities or career development (Durnian et al., 2011).

Surgery is an effective treatment for strabismus and generally improves individuals' well-being and health-related quality of life (HRQOL) (Adams et al., 2016; Hatt et al., 2010, 2012; McBain et al., 2016). However, some individuals do not experience improvement in their psychosocial HRQOL after surgery (Adams et al., 2016) and additionally, the surgical treatment or other suitable care is not always available to all individuals due to funding or misinformation of strabismus among healthcare providers (Buffenn, 2021; Marsh, 2015; Paduca et al., 2021). Therefore, it is necessary to assess the impacts of strabismus using a valid patient-reported outcome measure to gain information of patients' experiences and support clinical decision making (Lavallee et al., 2016).

The Adult Strabismus Questionnaire (AS-20) is a valid 20 item patient-reported outcome measure (PROM) for evaluating both psychosocial and functional HRQOL in strabismic adults. Each item has a five-point Likert scale of never, rarely, sometimes, often and always. The patients' responses are graded as never accounts 100, rarely 75, sometimes 50, often 25 and always 0 points. The overall HRQOL score is a mean sum of all the completed items and the scores range from 0 to 100. Low scores indicate a low HRQOL (Hatt et al., 2009a).

In Rasch analysis by Leske et al. (2012), four subscales of AS-20, self-perception, interaction, reading function and general function, were identified to measure the impacts of strabismus better than the original two, functional and psychosocial, subscales. Two of the original items are not included for the scoring in the refined AS-20 and the HRQOL scores are calculated by applying a look-up-table or by calculating the mean sum of the completed items. The HRQOL scores are reported by subscales (Leske et al., 2012). The validity of the refined AS-20 is supported by Leske et al. (2016) and use of the refined AS-20 is recommended for research (Leske et al., 2012).

The Finnish version of AS-20 has been recently translated and adapted into the Finnish language by assessing three different structures of AS-20: the original AS-20, the original AS-20 with Finnish addition and the refined AS-20. The refined AS-20 with 18 items and four subscales was found to be the most satisfactory structure for the Finnish AS-20, particularly for research use (Mason et al., 2023).

This cross-sectional study reports the associations between health-related quality of life, and demographic, self-reported strabismus-related and orthoptic status variables in Finnish strabismic adults. The frequencies and percentages of demographic and self-reported strabismus-related variables and median of participants' HRQOL scores have been previously reported (Mason et al., 2023).

2 | MATERIALS AND METHODS

2.1 | Study population

The sample for this study were adult patients (n=137) who participated in our previously reported validation study of the translated Finnish AS-20 (Mason et al., 2023). Inclusion criteria were generally healthy Finnish speaking strabismic adults (\geq 18 years of age) who were referred for treatment to the university hospital's strabismus clinic between December 2019 and December 2020, and voluntarily participated by signing an informed consent. Exclusion criteria consisted of cognitive difficulties, thyroid eye disease or critical health conditions such as brain or heart infarcts, and other serious physical and mental illnesses. Common eye diseases, such as cataracts, were not exclusion criteria.

Multi-professional staff at the clinic recruited participants purposefully. The participation was voluntary and did not impact the patients' care. The sample size was based on the requirements of instrument validation (Hair et al., 1998; Mason et al., 2023). In total, 150 patients signed the written informed consent and received the questionnaire with Finnish AS-20 with background and strabismus-related questions. Questionnaires were returned by 138 participants, but one patient was excluded due to a recent serious health condition, therefore 137 patients participated in the study. Participating patients' orthoptic status was collected separately from electronic patient data by two researchers (AM, LL) between 2020 and 2021. The study was conducted following the tenets of the Declaration of Helsinki, and ethical approval and research permission were received from HUS Helsinki University Hospital.

2.2 | Measurements

2.2.1 | Background and self-reported strabismus-related variables

Demographic data included questions on year of birth, gender and highest education which was categorized into comprehensive, diploma, degree and licentiate or PhD. Age was calculated from the year of birth and categorized into four categories (18–30-, 31–44-, 45–63- and 64–84-year-olds). Self-reported strabismus-related questions consisted of presence and visibility of strabismus (yes/no), effect of strabismus on work (no, yes partly, yes fully, not working), tiredness of the eyes, experience of diplopia, requirement of near vision for work or hobbies (yes/no) and number of strabismus surgeries performed (none, one, two, three or more).

2.2.2 | Finnish adult strabismus questionnaire AS-20

The Finnish AS-20 with 18 items in four subscales was chosen for this study as it is the most satisfactory structure for research (Mason et al., 2023). The HRQOL scores are graded separately for all four subscales calculating

the mean sum of all completed items. This mode of scoring is offered as an alternative scoring method by Leske et al. (2012).

2.2.3 | Orthoptic status

Orthoptic status included evaluation of the participants' binocularity and the deviation of the strabismic eye measured by prism dioptres both near and distance. Binocularity was assessed with Bagolini® striated glasses as part of the common practice. Deviation of the strabismic eye were categorized into five categories: esotropia (2-95Δ), exotropia (1-95Δ), vertical deviation (1-30Δ), esotropia and vertical deviation, exotropia and vertical deviation. Cyclodeviation was tested with Double Maddox rod (M2R) and categorized by no cyclodeviation (<5 deg) or cyclodeviation (≥5 deg). These limits were chosen by common clinical practice, and they are supported by Flodin et al. (2020) and Georgievski et al. (2007).

2.3 | Statistical analysis

To describe the data, frequencies and percentages were used for categorical variables and median, minimum and maximum for quantitative variables. While the distributions of AS-subscales were skewed (assessed by histograms, skewness values and Kolmogorov–Smirnov tests), the associations between participants' demographic, strabismus-related and orthoptic status and HRQOL were evaluated with nonparametric methods. Mann–Whitney U test was used for the variables with two categories, and Kruskal–Wallis test for the variables with three or more categories. The association between experienced diplopia and binocular vision was evaluated using cross-tabulation. Statistical significance was set at p < 0.05 (Munro, 2005). Data were analysed by the IBM SPSS Statistics version 25.

3 | RESULTS

Table 1 reports participant characteristics. One hundred and thirty seven of 150 consented patients participated in the study making the response rate 91%. Nearly, two-thirds were women (60%) and the biggest age group was 31–44-year-olds (32%); prime-age for working. Nearly, half of the participants had a degree, either bachelor's or master's (46%), and over half reported strabismus in one eye (55%). Most of the patients experienced tiredness of the eyes (89%) and needed near vision for work and hobbies (97%). Strabismus impacted individual's work, however, over half of the adults (52%) reported still managing in their role. A majority of the patients had never had strabismus surgery (56%), although over 10% had two or more surgeries. Cyclodeviation was found in 14% of the participating patients.

Table 2 shows the association between the experienced diplopia, and binocularity in distance and near viewing (cross-tabulation). More participants (63%) reported experiences of diplopia than was diagnosed in clinical

TABLE 1 Frequencies of self-reported socio-demographic and strabismus-related variables, and assessed cyclodeviation (n=137), Mason et al. (2023).

Mason et al. (2023).	•	
Background variables	n	%
Sex		
Male	56	40.9
Female	81	59.1
Age		
18–30	24	17.5
31–44	44	32.1
45–63	41	29.9
64–84	28	20.4
Education		
Comprehensive	23	16.9
Diploma	44	32.4
Degree (BSc or MSc)	63	46.3
Licentiate or PhD	6	4.4
Strabismus related variables		11.1
Presence of strabismus		
One eye	75	54.7
Both eyes	55	40.1
Not sure	6	4.4
Is strabismus visible	0	4.4
Yes	107	70.7
	107	78.7
No Time to the confidence of t	29	21.3
Tiredness of eyes	122	00.1
Yes	122	89.1
No	15	10.9
Experienced diplopia	0.6	60.0
Yes	86	62.8
No	51	37.2
Do you need near vision for work		
Yes	133	97.1
No	4	2.9
Does strabismus effect work		
No	22	16.1
Yes partly, doing own role	71	51.8
Yes fully, unable to perform in a own role	my 3	2.2
Not working currently	41	29.9
Previous strabismus surgery		
None	77	56.2
One	44	32.1
Two	12	8.8
Three or more	4	2.9
Cyclodeviation		
No cyclodeviation (<5 deg)	20	15
Cyclodeviation (≥5 deg)	19	14

examination of binocularity for both distance and near viewing. Nearly, three quarters (71%) of the patients who were examined to have normal retinal correspondence (NRC) reported experiences of diplopia for distance and over two-thirds (69%) for near.

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TABLE 2 Associations between experienced diplopia and binocularity distance and near viewing, cross-tabulation, (n=134).

NRC	Binocularity dis	stance viewing (n=1	134)	Binocularity ne		
	NRC (n=42) % (n)	Suppression $(n=53)\% (n)$	Diplopia (n=39) % (n)	NRC (n=52) % (n)	Suppression $(n=45)\% (n)$	Diplopia (n=37) % (n)
Yes (n=86)	71% (30)	40% (21)	85% (33)	69% (36)	40% (18)	81% (30)
No (<i>n</i> =51)	29% (12)	60% (32)	15% (6)	31% (16)	60% (27)	19% (7)

Abbreviation: NRC, normal retinal correspondence.

TABLE 3 Associations between participants' demographic and strabismus-related variables and Finnish AS-20 subscale scores (n=137), Mann-Whitney U and Kruskal-Wallis tests.

	AS-20	subscales										
	Self-perception			Interaction			Reading function			General function		
	Md	Range	p Value	Md	Range	p Value	Md	Range	p Value	Md	Range	p Value
All participants	60.0	0-100		87.5	10-100		50.0	0-100		43.8	0-100	
Sex												
Male $(n=56)$	60.0	15-100	0.061	90.0	20-100	0.158	62.5	0-100	0.038	50.0	0-100	0.001
Female $(n=81)$	55.0	0-100		87.5	10-100		50.0	0-100		37.5	6.3-75.0	
Age												
$18-30 \ (n=24)$	42.5	0 - 100	0.014	80.0	10-100	0.632	65.6	25-100	0.002	43.8	0-81.3	0.806
31–44 (<i>n</i> =44)	55.0	0 - 100		82.5	20-100		68.8	0 - 100		43.8	6.3-87.5	
45-63 (n=41)	70.0	15-100		90.0	15-100		43.8	0 - 100		43.8	6.3-100	
64-84 (n=28)	75.0	15-100		90.0	35-100		43.8	12.5-100		43.8	6.3-68.8	
Education												
Comprehensive $(n=23)$	60.0	0-100	0.848	85.0	15–100	0.442	50.0	12.5–100	0.064	43.8	12.5-87.5	0.819
Diploma (n=44)	60.0	0-100		90.0	10-100		46.9	0-93.8		43.8	0-75.0	
Degree (BSc or MSc) (n=63)	60.0	0-100		87.5	15–100		62.5	0–100		43.8	6.3–100	
Licentiate or PhD (<i>n</i> =6)	70.0	30-80		100	75–100		59.4	12.5-87.5		43.8	12.5-68.8	
Previous strabismus	surgery	7										
Yes (n=60)	55.0	0 - 100	0.026	80.0	20-100	0.008	53.1	6.3-100	0.141	43.8	6.3-100	0.570
No $(n=77)$	65.0	0-100		90.0	10-100		50.0	0 - 100		43.8	0-81.3	
Experienced diplopi	ia $(n=13)$	7)										
Yes (n=86)	70.0	0-100	< 0.001	90.0	10-100	0.002	46.9	0-100	0.001	43.8	6.3-81.3	0.031
No $(n=51)$	50.0	0-100		75.0	15-100		68.8	25-100		50.0	0-100	

Abbreviation: Md, Median.

Table 3 presents the associations between participants' demographic and strabismus-related variables and the Finnish AS-20 subscale scores. In overall, participants had the lowest HRQOL scores in general function and the highest in interaction subscales (Md 43.8, Md 87.5, respectively). Women had statistically significantly lower HRQOL scores than men both in reading (p=0.038)and general function (p=0.001) but not in self-perception or interaction subscales (Mann-Whitney U test). Participants' age had statistically significant association both in self-perception (p=0.014, Kruskal–Wallis test) and reading function (p=0.002). The youngest age group had lowest scores on self-perception and the two eldest groups on reading function. Educational background was not associated with HRQOL scores in any subscales.

Patients with previous strabismus surgery reported statistically significantly lower scores on self-perception (p=0.026) and interaction (p=0.008), however, not on reading and general function subscales. Additionally, self-reported diplopia showed statistically significant association on all four subscales. Participants with self-reported diplopia reported higher scores on self-perception (p < 0.001) and interaction (p=0.002) subscales, and lower scores on reading function (p=0.001) and general function (p=0.031) subscales.

Table 4 reports the associations of orthoptic status and the patients' HRQOL scores. There were statistically significant associations between binocular function, and both self-perception and interaction subscales in distance (p=0.001, p=0.005, respectively) and near viewing (p < 0.001, p = 0.001, respectively). Patients with NRC had higher HRQOL scores compared to the patients with suppression and diplopia. There were no statistically significant associations on either reading function or general function subscale scores between the groups.

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TABLE 4 Associations between orthoptic status and AS-20 subscale scores, n=137, Kruskal-Wallis test.

	AS-20 subscales											
	Self-perception			Interaction			Reading function			General function		
	Md	Range	p Value	Md	Range	p Value	Md	Range	p Value	Md	Range	p Value
Binocular function distance (n=	=134)											
NRC (<i>n</i> =42)	77.5	5-100	0.001	95.0	15-100	0.005	56.3	0 - 100	0.588	43.8	6.3-100	0.665
Suppression $(n=53)$	50.0	0 - 100		80.0	15-100		50.0	6.3-100		43.8	0-87.5	
Diplopia $(n=39)$	60.0	0 - 100		85.0	10-100		50.0	12.5-100		43.8	12.5-75.0	
Binocular function near ($n=134$	4)											
NRC (<i>n</i> =52)	82.5	15-100	< 0.001	97.5	15-100	0.001	50.0	0-100	0.920	43.8	6.3-100	0.554
Suppression $(n=45)$	50.0	0-100		80.0	15-100		50.0	6.25-100		43.8	0-87.5	
Diplopia $(n=37)$	55.0	0-100		80.0	10-100		62.5	12.5-100		43.8	12.5-75.0	
Strabismus distance ($n=137$)												
Esotropia (15% <i>n</i> =21)	65.0	20-100	0.302	90.0	15-100	0.103	50.0	0 - 100	0.695	43.8	6.3-75	0.803
Exotropia (19% n=26)	62.5	0 - 100		97.5	15-100		56.3	31.3-100		43.8	18.8-100	
Vertical strabismus $(7\% n=10)$	70.0	30-100		87.5	60–100		43.8	25-93.8		43.8	25–56.3	
Esotropia and vertical strabismus (19% <i>n</i> =26)	52.5	0-100		77.5	10-100		50.0	18.8–93.8		37.5	0-38.8	
Exotropia and vertical strabismus (39% <i>n</i> =54)	60.0	0-100		88.8	20–100		59.4	0-100		43.8	6.3-87.5	
Strabismus near $(n=133)$												
Esotropia (13% <i>n</i> =18)	60.0	5-100	0.274	85.0	15-100	0.223	62.5	0-100	0.842	40.6	6.3-75.0	0.354
Exotropia (26% n=35)	60.0	0-100		90.0	15-100		62.5	18.8-100		43.8	18.8-100	
Vertical strabismus (7% n=10)	70.0	15–100		91.3	20–100		43.8	12.5-87.5		37.5	18.8–56.3	
Esotropia and vertical strabismus (18% <i>n</i> =24)	55.0	0-100		82.5	10-100		53.1	18.8–93.8		40.6	0-68.8	
Exotropia and vertical strabismus $(34\% n=46)$	60.0	0-100		85.0	30-100		50.0	0-100		43.8	6.3-87.5	

Abbreviation: Md, Median.

Exotropia with or without vertical strabismus were most common among the patients both for distance (n=54, n=26, respectively) and near (n=46, n=35, respectively). There were differences in the HRQOL subscale scores with the patients in different groups, but the differences were not statistically significant.

4 | DISCUSSION

This present cross-sectional pilot study reports for the first time the associations between demographic, self-reported strabismus variables and orthoptic status, and the HRQOL scores in Finnish strabismic adults. Patients reported both functional and psychosocial impacts of strabismus as also seen in previous studies (Adams et al., 2016; Chang et al., 2015; Hatt et al., 2007; McBain, MacKenzie, et al., 2014). More participants reported experiences of diplopia than were assessed on the clinical examination both on distance and near viewing. It might be possible that assessment of diplopia at the clinic has been biased due to the short length of the examination, which may not allow enough time for the intermittent diplopia to be witnessed. It is known by clinical experience that some individuals, for example with large

intermittent exotropia, can align their eyes momentarily for the assessment and therefore not have diplopia in the assessment. Cyclodeviation was reported in 14% of this sample. However, since the sample was not recruited by orthoptic status but for AS-20 validation purposes and therefore the cohort is small, we are not able to estimate if cyclodeviation was a barrier to fusion as reported by Flodin et al. (2021).

Participants self-reported their experiences of diplopia in everyday life by replying yes or no on the questionnaire. In future studies, to gain a better understanding of the experiences on diplopia or even confusion, a valid diplopia questionnaire, for example, by Holmes et al. (2005) should be translated into Finnish and used for assessment. We can also discuss whether using Bagolini® striated glasses is a good enough method for assessing diplopia; however, it is easy and fast to use and common clinical practice in this department.

We expected to see lower median scores on the interaction subscale as we regularly meet patients with interaction difficulties and avoidance of gaze in our services, as reported by Hatt et al. (2007) and Wang et al. (2018). However, the median interaction subscale scores were the highest of all subscale scores

among the participants. Regarding participants' gender, women have been shown to have lower HRQOL than men (Durnian et al., 2010; Sah et al., 2017; Wang et al., 2013). However, in this study this was only seen in reading and general function subscales. The younger participants had lower scores on self-perception compared to the eldest; this could be due the appearance-related or self-esteem concerns of younger people. According to Paduca et al. (2021) appearance improvement and enhancement of self-esteem were strong incentives for young adults to seek strabismus surgery. Participants over the age 45 years had lower scores on reading function than 31–44-year-olds. This is an expected result as it is clinically known that accommodation weakens for the middle-aged patients, particularly with exotropia, and that causes strabismus to worsen and makes the reading more difficult. In the eldest age group other eye diseases are common and can have an impact on the reading function. In comparison to Wang et al. (2013), education level was not associated with HRQOL in strabismic adults of this study.

Patients who had previous surgery had lower scores on self-perception and interaction compared to the ones who had not had surgery. It is shown that for some individuals, surgery does not improve HRQOL (Hatt et al., 2018), however, this current study is cross-sectional so no causality can be assumed. Additionally, surgery was not recent for the participating patients. Clinical experience shows that although strabismus surgery was performed earlier it might not align the eye completely. Furthermore, it is not uncommon that esotropia operated in childhood turns into exotropia in adulthood or the existing exotropia angle increases, and the patients return to healthcare services for treatment.

It is worth considering that the participants who did not experience diplopia suffered from lower self-perception and interaction but reported higher scores on reading function and general function subscales in comparison to participants who reported diplopia. Similar results are reported in previous studies (Hatt et al., 2009b; McBain, Au, et al., 2014). This is a significant finding as in some publicly funded health-care systems, strabismus treatment might only be accessible for patients with functional problems from strabismus and the psychosocial side is not considered. It is recommended that treatment options are accessible to patients both with functional and psychosocial impact (Marsh, 2015).

We expected patients with confirmed diplopia to have lower reading and general function scores compared to the patients with NRC. As previously stated, there were patients who were not diagnosed with diplopia although they self-reported experiences of diplopia. It is also important to note that the general function subscale has items on worry and stress of strabismus (Leske et al., 2012) which might be shared by many of the participants regardless of their binocular status.

Exotropia with or without vertical deviation were the most common forms of strabismus in this study. This is supported by McBain, MacKenzie, et al. (2014) who

found the outwards deviation most common in their study participants. Regarding associations between HRQOL scores and the deviation of the eyes, previous studies state that individuals with exotropia have better HRQOL than the ones with esotropia (Sah et al., 2017; Wang et al., 2013). However, in the present study there were no significant differences in the median subscale scores between the groups, perhaps due to an unequal and small sample size.

There are limitations in this study. As participants were recruited for validation of the Finnish AS-20, inclusion criteria were based on validation purposes, which could have influenced this study's results. Translation of AS-20 into Finnish dictated that only Finnish speaking patients in an officially bilingual country (Finnish and Swedish) were included for the study; this should be noted when interpreting the results.

The cross-sectional nature of the study does not assume causality and longitudinal research is required to understand the effect of strabismus treatment in patients' HRQOL. As the participating patients were not recruited for cohorts based on the misalignment of the strabismic eye (exotropia vs. esotropia), the groups of deviation are not equal in size. It is worth noting that small sample size can influence the statistical testing. Therefore, we are not able to report the associations between magnitude of deviation and HRQOL in strabismic adults.

Further research should focus on longitudinal studies on HRQOL pre- and post-treatment, and the additional factors which might influence the HRQOL in Finnish strabismic adults. It is necessary to gain greater understanding on psychosocial impact of strabismus in Finnish adults, particularly in issues regarding interaction. Additionally, it is important to study the magnitude of deviation in equally sized cohort studies to gain knowledge whether the type of strabismus associates significantly with HRQOL scores.

5 | CONCLUSION

This first cross-sectional pilot study confirms that the impacts of strabismus on HRQOL shown in international studies are also seen in Finnish strabismic adults referred for treatment. The effect of strabismus should be measured both in clinical services and studied longitudinally to improve care and HRQOL in strabismic patients. Healthcare professionals and decision-makers should always consider the psychosocial impacts of strabismus on patients, even without diplopia, when making decisions on strabismus treatment and care processes.

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Anna Mason https://orcid.org/0000-0003-0674-8442

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