

ANNA MASON

# Health-Related Quality of Life in Finnish Strabismic Adults and Recommendations for Psychosocial Support



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Health-Related Quality of Life in Finnish  
Strabismic Adults and Recommendations  
for Psychosocial Support

ACADEMIC DISSERTATION

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I dedicate this dissertation to my mother Riitta Uski. With her strength, wisdom and commitment to me and my siblings, I grew strong wings already in childhood.

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Anna Mason

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# ABSTRACT

Strabismus is an ocular misalignment which impacts one's well-being and health-related quality of life. Strabismus is an umbrella term to many types of eye misalignments and the influence on well-being varies by different types and symptoms of strabismus. The influence of strabismus has been widely studied internationally in the fields of ophthalmology and orthoptics, but studies in terms of psychosocial health and support, or in nursing science are limited. Nationally the topic has not been studied before and this was the first study in the Finnish context.

The overall purpose of this study was to describe and explain the health-related quality of life (HRQOL) in strabismic adults and to provide recommendations for psychosocial support to strabismic adults. The main goals were to increase knowledge of the influence of strabismus on one's health-related quality of life with the public and multidisciplinary healthcare professionals, and to develop care, including psychosocial care, to enhance HRQOL among strabismic adults.

This study consisted of both quantitative and qualitative methodology in two phases. Both phases had two sub-studies each. The first sub-study aimed to translate and culturally adapt the Adult Strabismus Questionnaire (AS-20) into Finnish and evaluate the psychometric properties of the Finnish AS-20. The second sub-study examined associations between HRQOL and socio-demographic, self-reported strabismus-related and orthoptic status factors in Finnish strabismic adults using the AS-20. The third sub-study described the strabismic adults' experiences of psychosocial influences of strabismus, and the fourth their expectations for psychosocial support. In the summary, research findings were synthesised and consolidated into recommendations for psychosocial support to strabismic adults.

The research data included cross-sectional survey and clinical patient data (n=137), and semi-structured interview data (n=12) of strabismic adults who had been referred to university hospital's ophthalmology clinic for treatment of their ocular misalignment. In the quantitative phase, psychometric properties of internal consistency, convergent validity and construct validity of the newly translated Finnish AS-20 were evaluated. Evaluation was conducted in three different structures of the measure: the original AS-20, the original AS-20 with Finnish additions, and the refined AS-20. Data were described using descriptive statistics and

the associations were evaluated between socio-demographic, self-reported strabismus-related and orthoptic status variables, and HRQOL using Cross-tabulation and Chi-square test, and non-parametric methods. Inductive content analysis was used for analysing the qualitative data.

Translation of the Finnish AS-20 was clear and understandable, and the Finnish additions were relevant to the measure. All three structures were internally consistent and reliable as shown by Cronbach alpha values. The convergent validity, assessed by Spearman's correlation coefficients, showed low to moderate positive correlations between the structures and one item of Satisfaction with Life Scale. The construct validity, evaluated by confirmatory factor analysis, was the most satisfactory for the refined AS-20 structure. Patients had both psychosocial and functional struggles with strabismus, although interaction subscale showed surprisingly high scores indicating high HRQOL. Patient's age was significantly associated to HRQOL, and the younger participants had lower HRQOL in self-perception subscale than the older participants.

In the qualitative phase, the participants shared their experiences of psychosocial influences of strabismus and their expectations for psychosocial support from healthcare professionals. Participants described feeling challenged in social situations and struggled with mental well-being. These showed as stress in social situations, pressure in interactions, and emotional and psychological burdens of strabismus. The patients felt that psychosocial support would be needed, and they expected education of strabismus, genuine encounters with strabismus experts, accessible support and available peer support.

The proposed theoretical recommendations were synthesised and consolidated from the findings of all four sub-studies. The synthesised research evidence was deductively reflected, and recommendations were adapted into the Timing it Right framework with strabismic adults' care process. An understanding of the clinical patient services aided composition of the framework. The study results can be utilised for education of the general public and healthcare professionals in increasing awareness and development of clinical care, including psychosocial care and support for strabismic adults.

Keywords: strabismus, health-related quality of life, Adult Strabismus Questionnaire AS-20, psychometric properties, psychosocial support, inductive content analysis

# TIIVISTELMÄ

Karsastus on silmien virheasento, joka vaikuttaa yksilön hyvinvointiin ja terveyteen liittyvään elämänlaatuun. Karsastus on sateenvarjotermi monille silmien virheasentoille ja vaikutus yksilön hyvinvointiin vaihtelee laajasti riippuen karsastuksen tyypistä tai oireista. Karsastuksen vaikutusta on tutkittu laajasti kansainvälisesti silmätautien tai ortoptiikan tutkimuksissa, mutta hoitotieteellinen sekä psykososiaalisen terveyden ja tuen tutkimus aiheesta on rajallista. Karsastavien aikuisten terveyteen liittyvää elämänlaatua tai psykososiaalista tukea ei ole tutkittu aiemmin Suomessa.

Tämän tutkimuksen päätarkoituksena oli kuvata ja selittää terveyteen liittyvää elämänlaatua karsastavilla aikuisilla ja tuottaa psykososiaalisen tuen suosituksia. Päätavoitteina oli lisätä tietoa yhteiskunnassa ja moniammatillisissa terveyspalveluissa karsastuksen vaikutuksesta yksilön terveyteen liittyvään elämänlaatuun ja kehittää karsastavien aikuisten hoitoa, sisältäen psykososiaalisen tuen, jotta heidän terveytensä liittyvä elämänlaatunsa paranisi.

Tämä tutkimus oli kaksivaiheinen ja siinä hyödynnettiin sekä määrällisiä että laadullisia tutkimusmenetelmiä. Molemmat tutkimusvaiheet sisälsivät kaksi osatutkimusta. Ensimmäisen osatutkimuksen tarkoituksena oli kääntää ja kulttuurisesti muokata aikuisten terveyteen liittyvän elämänlaadun kysely Adult Strabismus Questionnaire (AS-20) suomeksi ja arvioida käännetyin kyselyn psykometrisia ominaisuuksia. Toisessa osatutkimuksessa tarkasteltiin yhteyksiä suomalaisten karsastavien aikuisten terveyteen liittyvän elämänlaadun ja sosiodemografisten, itseraportoitujen karsastusmuuttujien ja ortoptisen statuksen välillä käyttäen AS-20-mittaria. Kolmas osatutkimus kuvaili karsastavien aikuisten kokemuksia karsastuksen psykososiaalisista seurauksista ja neljäs heidän odotuksiaan psykososiaaliselle tuelle. Yhteenvedossa osatutkimuksen tuloksista tehtiin synteesi suosituksista aikuisten karsastavien psykososiaaliselle tuelle.

Tutkimuksen aineistot koostuivat 137 aikuisen potilaan kyselyn ja potilastietojärjestelmän tuottamasta aineistosta sekä 12 aikuisen puolistrukturoiduista haastatteluista. Aikuiset olivat hakeutuneet hoitoon karsastuksen vuoksi yliopistosairaalan silmätautien yksikköön. Määrällisessä vaiheessa tutkittiin suomalaisen AS-20-mittarin psykometrisia ominaisuuksia sisäisen

johdonmukaisuuden, rinnakkaisvaliditeetin ja rakennevaliditeetin keinoin. Mittarin kolme eri rakennetta arvioitiin. Mittariversiot olivat alkuperäinen AS-20, alkuperäinen AS-20 lisävääntämällä ja jatkokehitetty AS-20. Aineistoa kuvailtiin tilastollisten tunnuslukujen avulla. Muuttujien välisiä yhteyksiä tarkasteltiin sosiodemografisten, itseraportoitujen karsastusmuuttujien sekä ortoptisten statusmuuttujien ja terveyteen liittyvän elämänlaadun välillä käyttäen ristiintaulukointia ja khiin neliötä sekä epäparametrisia testejä. Laadullinen haastatteluaineisto analysoitiin induktiivisella sisällönanalyysillä.

Potilaat arvioivat suomenkielisen AS-20-mittarin käännöksen selkeäksi ja ymmärrettäväksi sekä lisävääntämät sopiviksi. Mittarin kaikki kolme rakennetta olivat sisäisesti johdonmukaisia Cronbachin alfan arvojen mukaan. Rinnakkaisvaliditeettia tutkittiin Spearmanin korrelaatiokertoimella ja se osoitti positiivista korrelaatiota AS-20-mittarin eri rakenteiden ja Satisfaction with Life Scale -mittarin yhden väittämän välillä. Rakennevaliditeettia arvioitiin konfirmatorisella faktorianalyysillä ja jatkokehitetty AS-20-rakenne todettiin kaikkein tyydyttävimmäksi rakenteeksi suomalaiselle AS-20-mittarille. Potilailla oli sekä psykososiaalisia että toiminnallisia haittoja karsastuksesta. Potilaat raportoivat hyvää terveyteen liittyvää elämänlaatua vuorovaikutuksen osa-alueella ja tämä tulos yllätti. Potilaiden iällä ja terveyteen liittyvällä elämänlaadulla oli tilastollisesti merkitsevä yhteys ja nuorimmilla potilailla oli heikompi minäkäsitys kuin vanhemmilla potilailla.

Tutkimuksen laadullisessa vaiheessa kuvattiin osallistujien kokemuksia karsastuksen psykososiaalisista seurauksista ja heidän odotuksiaan terveydenhuollon ammattilaisten tarjoamalle psykososiaaliselle tuelle. Osallistujat kokivat sosiaaliset tilanteet haasteellisiksi ja kamppailivat henkisen hyvinvointinsa kanssa. Nämä näyttäytyivät stressinä sosiaalisissa tilanteissa, paineena vuorovaikutuksessa ja karsastuksen emotionaalisenä ja psykososiaalisena kuormana. Potilaat kertoivat, että psykososiaalinen tuki olisi tarpeellista ja he odottivat sen olevan ohjausta ja koulutusta karsastuksesta, aitoja kohtaamisia karsastuksen ammattilaisten kanssa sekä helppopääsyistä ja saatavilla olevaa tukea.

Ehdotetut teoreettiset suositukset karsastavien aikuisten psykososiaaliselle tuelle ovat neljän osatutkimuksen tuloksista deduktiivisesti reflektoiden muodostettu synteesi. Suositukset esitetään Timing it Right -viitekehityksen mukaisesti huomioiden karsastavien aikuisten hoitoprosessi. Kliinisen potilashoidon ymmärtäminen auttoi suositusten laatimisessa viitekehitykseen. Tutkimustulosten avulla voidaan lisätä yhteiskunnan ja terveydenhuollon ammattilaisten tietoisuutta karsastuksen haitoista ja kehittää kliinistä potilashoitoa, myös psykososiaalista tukea, karsastaville aikuisille.

Asiasanat: karsastus, terveyteen liittyvä elämänlaatu, Adult Strabismus Questionnaire AS-20, psykometriset ominaisuudet, psykososiaalinen tuki, induktiivinen sisällönanalyysi

# CONTENTS

1	INTRODUCTION.....	19
2	REVIEW OF THE LITERATURE.....	21
2.1	Literature search.....	21
2.2	Influences of strabismus on individuals' health-related quality of life and treatment of strabismus.....	26
2.3	Instruments to measure health-related quality of life in strabismic adults .....	31
2.4	Psychosocial support for adults with ophthalmic conditions or facial disfigurements.....	35
2.5	Summary of literature review .....	38
3	PURPOSE AND THE AIM OF THE RESEARCH AND THE RESEARCH QUESTIONS .....	40
4	MATERIALS AND METHODS.....	42
4.1	Research designs.....	42
4.2	Setting of the study.....	42
4.3	Translation and psychometric properties of the Finnish AS-20, and the HRQOL in strabismic adults (sub-studies I-II) .....	44
4.3.1	Instruments .....	44
4.3.2	Participants and data collection.....	45
4.3.3	Analysis of the data .....	46
4.4	Psychosocial influences of strabismus and expectations for psychosocial support (sub-studies III-IV).....	47
4.4.1	Participants and data collection.....	47
4.4.2	Analysis of the data .....	49
4.5	Formulation of recommendations.....	50
5	RESULTS.....	52
5.1	Characteristics of the participants.....	52
5.2	Translation and validation of the AS-20 into Finnish (sub-study I).....	53
5.3	HRQOL in Finnish strabismic adults (sub-study II) .....	55
5.4	Psychosocial influences of strabismus in Finnish adult patients (sub-study III) .....	57

5.5	Strabismic adult patients' expectations of psychosocial support from healthcare professionals (sub-study IV) .....	58
5.6	Recommendations for psychosocial support to strabismic adults (summary) .....	59
6	DISCUSSION.....	62
6.1	Overview of the findings.....	62
6.1.1	Translation and validation of the AS-20 into Finnish (sub-study I).....	62
6.1.2	HRQOL in Finnish strabismic adults (sub-study II).....	63
6.1.3	Psychosocial influences of strabismus in Finnish adult patients (sub-study III).....	64
6.1.4	Strabismic adult patients' expectations of psychosocial support from healthcare professionals (sub-study IV).....	65
6.1.5	Recommendations for psychosocial support to strabismic adults (summary).....	67
6.2	Ethical considerations.....	68
6.3	Strengths and limitations of quantitative sub-studies I-II.....	70
6.4	Trustworthiness of qualitative sub-studies III-IV .....	73
6.5	Implications for practice.....	77
6.6	Further research recommendations .....	78
7	CONCLUSIONS.....	80
8	REFERENCES.....	81

### *List of Figures*

<b>Figure 1.</b>	Edited PRISMA flow diagram on literature search and data selection on health-related quality of life in strabismic adults.....	24
<b>Figure 2.</b>	Edited PRISMA flow diagram on literature search and data selection on psychosocial support and patients with ophthalmic conditions or facial disfigurements.....	25
<b>Figure 3.</b>	Participants' median AS-20 scores by the refined AS-20 subscales.....	56
<b>Figure 4.</b>	Proposed recommendations for psychosocial support for strabismic adults, based on Timing it Right framework by Cameron & Gignac, 2008 .....	60



## *List of Tables*

<b>Table 1.</b>	Condition-specific instruments on measuring HRQOL in strabismic adults .....	34
<b>Table 2.</b>	Summary of the research design, setting, materials and methods.....	43
<b>Table 3.</b>	Participant characteristics of sub-studies III and IV .....	52
<b>Table 4.</b>	Descriptive statistics, psychometric properties and model fit indicators of three Finnish AS-20 questionnaire structures and their subscales.....	54

# ABBREVIATIONS AND DEFINITIONS

Amblyopia	Visual impairment due to lack of functional maturation of the eye
AS-20	Adult Strabismus Questionnaire
A&SQ	Amblyopia and Strabismus Questionnaire
Binocular function	Ability of the brain to fuse two pictures into one
Congenital esotropia	Congenital visible strabismus, eye deviates inwards
Cyclodeviation	Eye rotates around its axis
Diplopia	Double vision
Esotropia	Visible strabismus, eye deviates inwards
Exotropia	Visible strabismus, eye deviates outwards
HRQOL	Health-related quality of life
Hypertropia	Visible strabismus, eye deviates upwards
Hypotropia	Visible strabismus, eye deviates downwards
Intermittent exotropia	Eye deviates outwards intermittently
NRC	Normal retinal correspondence
Orthoptic status	Measurement and clinical assessment of strabismus
PROM	Patient-reported outcome measure
QOL	Quality of life
VF-25 (also NEI VF-25)	Visual Function Questionnaire by National Eye Institute
Visual confusion	A form of visual distraction due to misalignment

# LIST OF ORIGINAL PUBLICATIONS

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Publication IV Mason, A., Joronen, K., Lindberg, L., Kajander, M., Fagerholm, N., & Rantanen, A. Strabismic adults' expectations of psychosocial support from healthcare professionals – A qualitative descriptive study. Submitted

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This study includes unpublished results.



# 1 INTRODUCTION

Strabismus is an eye condition where the eyes are misaligned and therefore focus on different directions. Strabismus types can be defined by the direction, visibility or presence of the deviation. Horizontal deviations exotropia (eye turns outwards) and esotropia (inwards) are more common than vertical deviations (upwards or downwards). Individuals might have either horizontal or vertical strabismus, or a combination of these two types. Deviation may be constant or intermittent and, in some people, deviation alternates between the eyes. The eye can also be rotated around its own axis (cyclodeviated). Strabismus is most commonly visible to others (tropia), although some have non-visible strabismus (phoria). (Assaye et al., 2020; Buffenn, 2021; Fieß et al., 2020; MacKenzie et al., 2016.) Strabismus is present in all age groups and worldwide population prevalence is calculated at nearly two percent. In global adult population, 3–4 % have strabismus. (Hashemi et al., 2019; Marsh, 2015.) According to pooled estimates, strabismus is more prevalent in western countries and white people in comparison to Asian ethnicities (Hashemi et al., 2019).

In adults, strabismus might be childhood-onset or acquired in adulthood due to other conditions, such as cranial nerve palsies, neurological diseases, thyroid eye disease, trauma or vision loss (Al-Omari et al., 2022). Strabismus impacts one's health-related quality of life (HRQOL) both on general and psychosocial functioning (Adams et al., 2016; Chang M. et al., 2015; Hatt et al., 2007). The impact varies on strabismus type, onset, aetiology and symptoms, particularly diplopia (double vision). Individuals with adult-onset strabismus have more often diplopia and visual confusion as strabismus affects their ability to integrate two images into one. Whereas, adults with childhood-onset strabismus do not suffer as often from diplopia, as they have either never developed the ability to integrate two images due to childhood strabismus or their brain has learnt to suppress images they see with the strabismic eye. (Kraus & Kuwera, 2023.) Diplopia has more impact on functional than psychosocial HRQOL (Buffenn, 2021).

Psychosocial support as part of psychosocial care is important to a holistic approach to patients, but has often been underestimated and under researched in clinical ophthalmic care (Watkinson & Williamson, 2023). With a holistic approach

the professional sees the patient from head to toe and gains an in-depth understanding of the challenges the patient has with their condition and how to support their well-being. In specialised healthcare, strabismic adults are cared for by a multidisciplinary team of nurses, ophthalmologists, optometrists and orthoptists. Nurses are an integral part of multidisciplinary team with holistic care approach as the core of their profession (Watkinson & Williamson, 2023). Nursing professionals have an important role for developing patients' holistic care (Persson & Carlson, 2019). As nurses have an overarching role in the multidisciplinary team and have an overview of the whole healthcare spectrum (Lindahl Norberg & Strand, 2022), nurses need to be involved in developing also strabismic patient services using evidence-based research.

It is worth noting that not all people living with strabismus struggle with the impacts of their condition and seek help. Therefore, the participants in this study are patients who have sought help for strabismus from a public specialised healthcare. In Finland, these patients are referred to ophthalmology departments by either primary care or private physicians. Patients with health care insurance or own funds can also acquire treatment privately.

It is important to assess the impacts of strabismus and the care, and develop patient services using patient-reported outcome measures (Lavalley et al., 2016). Furthermore, there is a concern that strabismus surgery for psychosocial reasons to adults without diplopia could be restricted due to financial situations in many publicly funded healthcare systems. This is already the situation in some areas of England. (Arblaster et al., 2024a; El Meshad et al., 2024.) It is yet unknown how these restrictions may impact mental health or employment services, but potentially the demand for these services would increase as strabismus has psychosocial and economical influences on adults (El Meshad et al., 2024).

This study in nursing science focuses on strabismic adult patients, their health-related quality of life and expectations for psychosocial support. The study aims to increase knowledge for the influences of strabismus and to develop the patient services, including psychosocial support for strabismic adults. This has not been studied previously in Finnish context. Based on literature searches, studies in nursing science focusing on ophthalmic patients are not common. This study consists of four sub-studies and a summary. The results of this study provide a translated and adapted Finnish measure to assess HRQOL, new knowledge on Finnish strabismic patients' HRQOL and psychosocial influence of the condition, and recommendations for psychosocial support to the patients.

## 2 REVIEW OF THE LITERATURE

### 2.1 Literature search

The theoretical framework of this study consists of published literature of strabismus and treatment impacting individual's health-related quality of life (HRQOL), and the instruments which are used to measure HRQOL of strabismic patients. As the published literature of psychosocial support for strabismic patients is limited, literature searches were extended into psychosocial support in ophthalmic patients and patients with facial disfigurements. The central concepts in this study are strabismus, strabismic adults or strabismic adult patients, health-related quality of life and psychosocial support.

In this study strabismus is defined as an ocular condition with visible or objectively measured non-visible misaligned eye(s). Strabismic adults or strabismic adult patients in this study are not all people living with strabismus, but adults aged 18 years or over who have sought help from health care for their condition. English translation of Finnish Act on the Status and Rights of Patients define patient as "a person who uses health care services or is otherwise an object of them" and the Regional State Administrative Agency describes that a patient has rights to access treatment (AVI, 2024; FINLEX, 1992). In this study the terms patient and adult are used interchangeably.

Health-related quality of life (HRQOL) can be defined as individual's functioning and well-being in mental, physical and social aspects of life (Kaplan & Hays, 2022). Health-related quality of life and quality of life (QOL) are similar concepts. However, HRQOL assesses how an individual's health, illness or treatments affect their functional abilities and physical, mental and social well-being whereas QOL refers to all aspects of an individual's life. (Ferrans et al., 2005; Guyatt et al., 2007; Hays & Morales, 2001.) Additionally, work-related activities, such as career is also considered an aspect of HRQOL (Hays & Morales, 2001; Kaplan & Hays, 2022). HRQOL can be assessed using generic or condition-specific measurements (Carlton & Kaltenthaler, 2011; Hays & Morales, 2001). When assessing HRQOL in strabismic patients, condition-specific instruments are likely more sensitive to assess the effect of strabismus (Carlton & Kaltenthaler, 2011). Patients need to self-evaluate their

HRQOL and the evaluation should be regular in clinical practice (Carlton & Kaltenthaler, 2011; Lin et al., 2013). Assessing HRQOL in both research and clinical practice can be used to improve patient services and patient outcomes (Carlton & Kaltenthaler, 2011; Guyatt et al., 2007; Lavalley et al., 2016). In this study, HRQOL is defined as of how strabismus and its' treatments influence physical function, and physical, mental, social and economic well-being of strabismic adult patients in healthcare services.

Psychosocial support can be seen as actions and processes that enhance an individual's "holistic well-being in the social world" (INEE, 2018). In healthcare this shows as supporting patients' and their families' in their emotional, mental, social, spiritual and informational needs (Gallienne et al., 1993; NCI, 2024). Psychosocial support systems are organised activities aiming to "address ongoing psychological and social problems of individuals, their partners, families and caregivers" (NLM, 2024). In this study psychosocial support is defined as actions to support strabismic adult patients' emotional, mental, social, spiritual and informational needs.

Literature search consisted of two separate searches. The search terms and databases were discussed with the information specialists at the Tampere University library and preliminary searches were conducted. The literature search was extended to include patients with ophthalmic conditions and facial disfigurements since the preliminary searches indicated lack of research in psychosocial support among strabismic adults. Additionally, preliminary searches showed the lack of research in Finnish language and therefore the Finnish language database Medic was not used. The first search was conducted for health-related quality of life (HRQOL) in strabismic adults, and the second search for psychosocial support in patients with ophthalmic conditions or facial disfigurements.

The literature for HRQOL in strabismic adults was searched in November 2023 from Medline Ovid, PubMed, CINAHL and PsycInfo. The search terms used were strab\*, squint, exotropia, esotropia, ocular deviation, diplopia, double vision, health-related quality of life, HRQOL, quality of life, QOL, well-being, quality of life measures, health outcome\* and psych\* well-being. The terms were combined with AND or OR commands. The search aimed at finding impacts and influences of strabismus on adults' HRQOL, measurements, treatments and support from healthcare services. The search was updated in July 2024 using Medline Ovid and PubMed as all the results in November 2023 search came from these two databases.

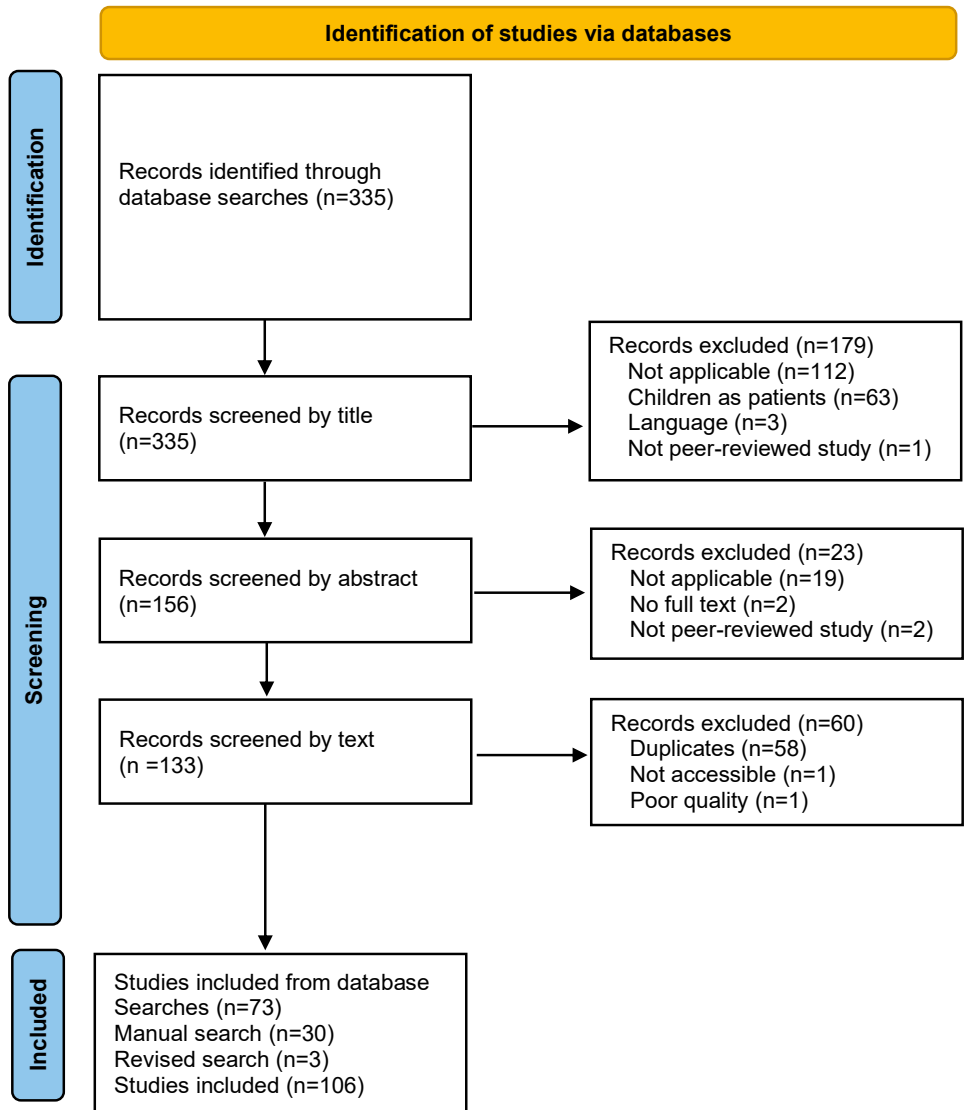
Inclusion criteria were peer reviewed articles in English language from 1993 to date with full-text available and with strabismic adults as main participants.



Exclusion criteria consisted of strabismic children or adolescents or adults with other ophthalmic conditions. Manual search from reference lists of published studies, books and Google Scholar was used to extend the database searches. The search produced 335 studies of which 73 were included. Manual search produced 30 studies which were accepted and therefore, the total number of studies for the search in November 2023 was 103. The updated search in July 2024 produced three more peer-reviewed articles published in 2024 totalling studies to 106. Figure 1 describes the search and data selection.

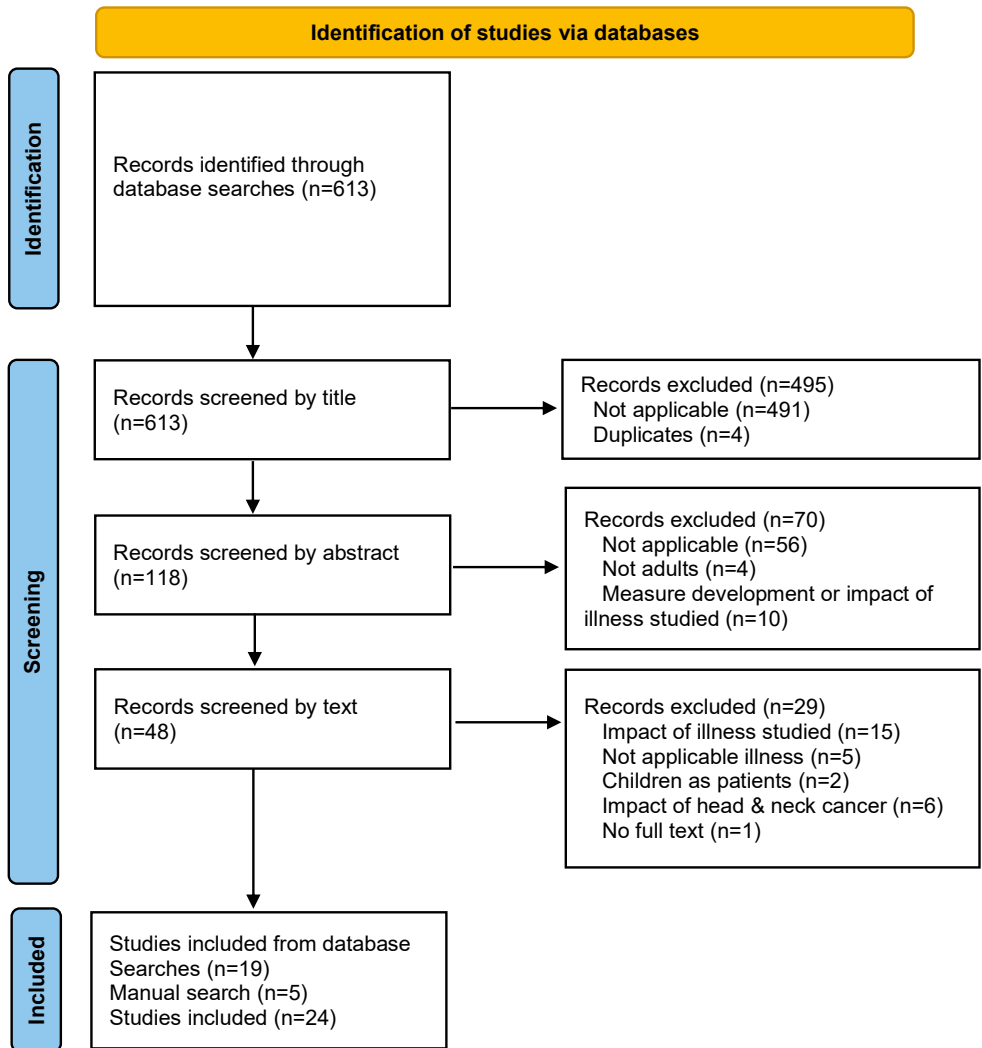
The literature for psychosocial support and ophthalmic conditions or facial disfigurements was searched in March 2024 from Medline Ovid, CINAHL, PsycInfo and Social Science Database. The terms used for these searches were psychosocial support, support, psychosocial factor\*, eye disease\*, ocular disease\*, facial disfigur\*. Boolean operators of AND and OR were used to combine the terms. Inclusion criteria were peer reviewed full-text articles in English language from 1999 until March 2024 which described 1. what kind of psychosocial support patients or healthcare professionals expect, 2. what kind psychosocial support is available for adults with ophthalmic conditions or facial disfigurements or 3. what kind of psychosocial support has helped the patients. Exclusion criteria were studies with children or adolescents as main participants or research which aimed to study the psychosocial impact of ocular disease or facial disfigurement. Articles which studied patients with head and neck cancer were excluded unless they described patients' needs for psychosocial support due to facial disfigurement. The search produced 613 studies of which 19 were included. Additional manual search from reference lists of published peer-reviewed articles and published books produced 5 references which were included in the search. This increased the total number of references to 24 of which 20 addressed psychosocial support with ocular diseases and four with facial disfigurement. One of the four studies of patients with facial disfigurement focused on patients with head and neck cancer. Figure 2 describes the search and data selection.

**Figure 1.** Edited PRISMA flow diagram on literature search and data selection on health-related quality of life in strabismic adults.



*Edited From:* Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71

**Figure 2.** Edited PRISMA flow diagram on literature search and data selection on psychosocial support and patients with ophthalmic conditions or facial disfigurements



*Edited From:* Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71

## 2.2 Influences of strabismus on individuals' health-related quality of life and treatment of strabismus

The results of the literature review showed that strabismus can have wide influence on individual's health-related quality of life and well-being, particularly assessed from functional, psychological, social, economic, mental and general health perspectives. Strabismus may cause various symptoms which have direct or indirect impact on HRQOL. As strabismus can manifest multiple ways and the deviated eye may alternate or the deviation might be intermittent (MacKenzie et al., 2016), the influence may vary from one type of strabismus to another.

### *Social, psychological and emotional influence*

Strabismic adults reported struggles with social life and interactions with peers, lower interpersonal skills, troubles making eye contact, embarrassment in interactions, avoidance of social situations, difficulties in making and managing relationships and gaining others' trust (Durnian et al., 2011; Hatt et al., 2007; Menon et al., 2002; Nelson et al., 2008; Olitsky et al., 1999; Xu J. et al., 2012). Adults tried to hide their strabismus by rubbing the deviated eye, having long hair to cover face or looking down avoiding gaze in social situations (Marsh, 2015). When comparing adults and children, adults felt more struggles in interpersonal relationships than children. However, both groups stated that other people notice their strabismus and that caused feelings of inferiority in social situations. (Bandhu et al., 2023.)

Having strabismus affected one's emotions and self-perception. Studies reported strabismic adults with lack of self-confidence and negative self-esteem. Feelings of lower self-identity and self-acceptance compared to visually healthy adults, feelings of inferiority and sadness and non-specific negative feelings were described. (Bian et al., 2015; Hatt et al., 2007; Kim et al., 2016; Nelson et al., 2008; Ribeiro et al., 2014; Wang Z. et al., 2018; Xu J. et al., 2012.) As strabismus changed facial symmetry, it impacted appearance affecting one's own feelings of attractiveness or others' perceptions of their attractiveness or appearance (Bian et al., 2015; Buffenn, 2021; Felius et al., 2007; Marsh, 2015; Mojon-Azzi et al., 2008; Ortiz Montero et al., 2023; van de Graaf et al., 2004; Wang Z. et al., 2018). Wang Z. et al. (2018) further noted that these facial and ocular appearances reduced the willingness of people to be photographed.

Strabismic patients seemed to experience symptoms of depression and anxiety (Adams et al., 2016; Alpak et al., 2014; Ehlers et al., 2023; McBain et al., 2014a). When compared to other chronic diseases, strabismic adults showed higher clinical

levels of depression and anxiety similar to individuals with facial disfigurements (McBain et al., 2014a). Higher depression scores were associated with lower HRQOL on interaction, reading function and general function assessed on AS-20 (Hatt et al., 2014a). Retrospective registry studies of children with strabismus, children with intermittent exotropia or congenital esotropia reported of increased mental health disorders by adulthood (McKenzie et al., 2009; Mohny et al., 2008; Olson et al., 2012). The risk for mental disorders showed also for the patients with adult-onset strabismus when compared to non-strabismic control group (Hassan et al., 2015). Additionally, social phobia was more common in strabismic adults compared to non-strabismic adults thus causing more disability at work or family lives (Bez et al., 2009).

#### *Functional well-being*

Strabismus impacted functional eyesight, such as visual disorientation and confusion, diplopia and poor eyesight. Ocular, back, head and neck pain, eye fatigue and burning sensation in the eyes were common. Many strabismic adults had abnormal posture as they tried to manage diplopia with movements of the head. (Chang M. et al., 2015; Kumaran et al., 2019; Wang Z. et al., 2018.)

The symptoms influenced daily life, for example in difficulties with driving, reading, watching TV, cooking, playing sports or enjoying hobbies. Strabismic adults struggled with depth perception causing use of mobile devices to be difficult. Functional symptoms of strabismus influenced the choices for career as some professions require clear eyesight and good depth perception. (Chang M. et al., 2015; Hatt et al., 2007; Kumaran et al., 2019; Ribeiro et al., 2014; van de Graaf et al., 2004; Wang Z. et al., 2018.) Adults with diplopia struggled more with physical functioning whereas adults without diplopia had more psychosocial concerns (McBain et al., 2014b). There are increased risks for falling or injuries associated with strabismus and thus strabismus is considered a public health concern (Buffenn, 2021; Wang Z. et al., 2018).

#### *Social bias and influence on employment*

Adults with strabismus faced social bias, such as teasing and bullying from others in social situations, struggles in romantic relationships or decreased possibilities for employment (Mojon-Azzi et al., 2008; Mojon-Azzi & Mojon, 2007; Mojon-Azzi & Mojon, 2009; Wang Z. et al., 2018). These were shown for example in studies where headhunters, dating agents and other professionals assessed artificially induced strabismus in adults and rated the strabismic adults as less intelligent with poor

personality traits and communication skills, therefore limiting their employability or chances of finding a partner (Kothari & Joshi, 2014; Mojon-Azzi & Mojon, 2009; Olitsky et al., 1999). Photos with strabismic women or adults with esotropia received lower scores on hiring preference or promotion compared to photos with strabismic men or non-strabismic adults (Coats et al., 2000; Goff et al., 2006; Mojon-Azzi & Mojon, 2009). However, according to the newest research, altered photos of strabismic men were rated as needing greater intervention than females with the same condition. Additionally, altered photos of adults with larger deviation or exotropia were assessed as requiring treatment more than the photos of adults with smaller deviation or esotropia. (Thuma et al., 2023.)

### *HRQOL in strabismic adults*

Strabismic adults reported lower quality of life and well-being compared to the non-strabismic adults or adults with other eye conditions when measured in QOL instruments (Alamri et al., 2022; Ali et al., 2015; Al-Omari et al., 2022; Bian et al., 2015; Fieß et al., 2020; Sah, 2017; Yu et al., 2013; Zhao et al., 2021). Strabismic women had lower HRQOL compared to men (Ali et al., 2015; Al-Omari et al., 2022; Durnian et al., 2010; Felius et al., 2007; Glasman et al., 2013; Power et al., 2018; Sah, 2017; Wang Z-H. et al., 2013) although studies reported also no difference between sexes (Yu et al., 2013) or strabismic women having higher HRQOL than strabismic men (Alamri et al., 2022). Young patients or patients who were younger at onset of strabismus had lower psychosocial health compared to the patients who were older at onset of strabismus (Felius et al., 2007; Hatt et al., 2014a). Regarding education, it seemed that higher education was associated significantly with higher functional well-being (Wang Z-H. et al., 2013) whereas strabismic patients with lower socioeconomic status or females from more deprived areas, reported lower well-being on HRQOL measurement (Durnian et al., 2010; Sim et al., 2018).

Strabismus-related variables impacted the individual's well-being and HRQOL. There is no conclusive evidence, whether the size or the angle of deviation is related to the scores of HRQOL measurements. No associations were found between the reduced HRQOL and the size of deviation or angle of strabismus indicating that having visible strabismus affects adult's psychosocial health and it does not matter how large or small the angle is (Ritchie et al., 2013). However, other studies reported associations between larger deviation and lower psychosocial health or lower HRQOL on self-perception, interaction and general function (Al-Omari et al., 2022; Hatt et al., 2014a). Adults with esotropia struggled more with their psychosocial and functional health than those with exotropia (Sah, 2017). Whereas non-diplopic adults

reported lower overall and psychosocial scores on AS-20 compared to diplopic adults (Sim et al., 2018). Adults with cyclodeviation showed overall lower scores on HRQOL measurement compared to adults without cyclodeviation (Flodin et al., 2021).

### *Surgery and treatment of strabismus*

Most studies assessed the effect of corrective strabismus surgery to HRQOL. Although surgery is the most common, it is not the only, treatment option. Depending on the symptoms of strabismus, prism lenses and botulinum toxin injections can also be used to treat strabismus and their use improved patients' health-related quality of life, reading function and general function (Hancox et al., 2012; Hatt et al., 2014b).

Strabismic adults sought treatment for various reasons. Motivations for surgery included difficulties with vision, appearance, psychosocial, and employability reasons (Adams et al., 2016; Al-Omari et al., 2022; Paduca et al., 2021; Sandercoe et al., 2014). When studying utility of strabismus prior surgery, patients were prepared to trade part of their life expectancy to get rid of their condition and this showed association with disability measures. Same willingness was not reported with the non-surgical strabismic adults. (Beauchamp GR. et al., 2005a.)

Corrective surgery was shown as cost-effective (Beauchamp CL. et al., 2006; Fujiiike et al., 2011) and improved overall health-related or vision-related quality of life and the varied subscales of the available measures, such as psychosocial and functional well-being and general and mental health (Alam et al., 2014; Arblaster et al., 2024b; Dickmann et al., 2013; El Meshad et al., 2024; Flodin et al., 2021; Fujiiike et al., 2011; Jackson et al., 2006; Khurana et al., 2021; Kishimoto & Ohtsuki, 2012; Koc et al., 2013; McBain et al., 2016a; Power et al., 2018; Sim et al., 2018; Wang JY. et al., 2019; Xu M. et al., 2016; Yao et al., 2019). Patients who had poor binocular function pre-operatively reported increase also in functional as well as psychosocial HRQOL post-operatively (Khurana et al., 2021). Similarly, adult strabismic patients who had corrective surgery for psychosocial reasons reported post-operatively also functional benefits with improved vision and task performance as well as expected increase in confidence and emotions (Arblaster et al., 2024b).

Regarding the socio-demographic variables and HRQOL, lower socio-economic status was associated to significantly larger increase in HRQOL compared to the patients with higher socio-economic backgrounds (Sim et al., 2018). The improved post-operative HRQOL was also seen in older patients (Fang et al., 2018; Merrill et al., 2010) indicating that age alone should not restrict the treatment for strabismus.

The effects of disability from strabismus, such as specific health problems and difficulties in non-work related tasks in daily living, decreased post-operatively (Beauchamp GR. et al., 2005b). Patients who post-operatively still had the sense of deviation reported lower HRQOL than the patients who did not have the sense of deviation (Ji et al., 2020).

Functional benefits of surgery included extending individual's visual field, some restoration of binocularity, possible removal of diplopia and improved abnormal posture, distance estimation, general, and physical function (Dickmann et al., 2013; Ehlers et al., 2023; Gunton, 2014). Although patients without diplopia generally had more post-operative increase in psychosocial compared to functional well-being, surgery improved also concentration, depth perception, hobbies and eye strain in strabismic patients without diplopia (Hatt et al., 2012a; Liebermann et al., 2014).

Strabismus surgery reduced adults' clinical anxiety, depression, social phobia, social anxiety and social avoidance (Adams et al., 2016; Alpak et al., 2014; Ehlers et al., 2023; Jackson et al., 2006). Patients reported improved self-esteem, self-confidence, self-perception and perceptions of own appearance after strabismus surgery (Ehlers et al., 2023; Menon et al., 2002; Nelson et al., 2008; Xu J. et al., 2012). Individuals felt also a positive change in their interpersonal relationships post-operatively (Xu J. et al., 2012).

The improvement in well-being, quality of life, coping and satisfaction was long-lasting in patients with clinically successful surgeries (Hatt et al., 2012a; Jackson et al., 2013), although it was too early to see all the changes after six weeks post-operatively, which in some services was the last post-operative visit (Hatt et al., 2012b). It is noteworthy that even the patients whose surgeries were clinically unsuccessful or the surgery brought diplopia as a side effect, felt their health-related quality of life improved which showed as increased scores on HRQOL measurements (Hatt et al., 2016; Wang JY. et al., 2019). However, some individuals with clinically failed surgery reported decreasing scores in their well-being at one year post-operatively (Hatt et al., 2012a).

It is worth noting that although surgery had a positive influence on well-being, strabismic adults' post-operative scores on HRQOL did not reach the scores of non-strabismic adults (Glasman et al., 2013; Xu M. et al., 2016). Therefore, it is imperative to understand that other factors than clinical measures of strabismus influence on strabismic adults' well-being. It is important to assess what the patients' expectations for the surgery are, acknowledge the mental health aspects of strabismus and provide psychosocial support to patients pre-operatively to enhance the positive effect of



surgical correction. (Ehlers et al., 2023; Hatt et al., 2018; MacKenzie et al., 2016; McBain et al., 2016a; 2016b.)

## 2.3 Instruments to measure health-related quality of life in strabismic adults

Health-related quality of life in strabismic adults can be assessed with generic quality of life instruments. However generic measures may not be sensitive enough to assess the functional struggles with eyesight or psychological, social and emotional challenges strabismic adults face. Therefore, condition-specific instruments should be used. (Carlton & Kaltenthaler, 2011.) There are several different HRQOL measures or questionnaires to assess strabismic adults' health-related quality of life and well-being (Kumaran et al., 2018), although most studies focused on three instruments; National Eye Institute Visual Function Questionnaire (VFQ-25, also NEI-VFQ-25), Amblyopia and Strabismus Questionnaire (A&SQ) and Adult Strabismus Questionnaire (AS-20) (Carlton & Kaltenthaler, 2011; Hatt et al., 2009a; Hatt et al. 2010a; van de Graaf et al., 2004). These three instruments are presented in Table 1.

**The VFQ-25** is an English 25-item measure to assess health-related quality of life in ophthalmic conditions developed from the original 51-item measure (NEI-VFQ-51). It is originally developed to measure the impact of ocular diseases, such as age-related cataracts, age-related macular degeneration, diabetic retinopathy, primary open-angle glaucoma, cytomegalovirus retinitis, or low vision from any reason. The development of shorter measure was required as response burden was high for the original measure. The VFQ-25 has 25 items on subscales of general health, general vision, near vision, distance vision, driving, peripheral vision, colour vision, ocular pain, vision specific role difficulties, vision specific dependency, vision specific social functioning and vision specific mental health. Each subscale is scored from 0 to 100, the highest value representing the best possible score. (Mangione et al., 2001.)

**The A&SQ** is developed in the Netherlands, originally in Dutch language, and it can be used to assess HRQOL for adult patients with amblyopia and/or strabismus. The research group collected complaints from adults with these conditions. Complaints were then categorised in a focus group with professionals and two patients into three themes of loss of depth perception, diplopia and visual disorientation, and

appearance. The themes were further specified into five domains of “fear of losing the better eye”, “distance estimation”, “visual disorientation”, “diplopia” and “problems with social contact and cosmetic problems”. The response options were: none of the time = 1, a little of the time = 2, some of the time = 3, most of the time = 4, and all of the time = 5. The developed A&SQ was piloted on 16 amblyopic patients and further tested on three groups along with the SF-12 and the VFQ-25. The SF-12 is a generic questionnaire which measures the impact of health on daily life. Three groups were 1. amblyopic and strabismic patients (n=68), 2. visually healthy adults (n=53) and 3. historic cohort of amblyopic patients (n=174). The A&SQ showed acceptable discriminatory validity as the amblyopic and strabismic patients reported lowest QOL compared to the other groups. (van de Graaf et al., 2004.) A&SQ was further clinically validated and construct validity assessed by factor analysis (van de Graaf et al., 2007, 2009). A&SQ has been assessed as an appropriate measure for strabismic and amblyopic individuals (Vianya-Estopa et al., 2010). The English translated version is abbreviated as A&SQE (Feliuss et al., 2007) and other translations include Chinese, Turkish and Italian (Bian et al., 2015; Çoşkun et al., 2017; Marcon & Pittino, 2014).

**The AS-20** is a patient-reported outcome measure developed in the USA (Hatt et al., 2009a). In the first phase the developers interviewed 30 strabismic adults on the influence of strabismus on their well-being and health-related quality of life (Hatt et al., 2007). The interviews produced 181 items with response options of never, rarely, sometimes, often, always and not applicable. The items were then answered by 29 strabismic adults. Items that had over 10 % response rate of ‘not applicable’ or over 80 % of ‘never/rarely’ or ‘often/always’ were removed. Additionally, the items which focused purely on symptoms of strabismus or were discriminative to some patients were also removed. Factor analysis indicated two factors, psychosocial and functional subscales. To maintain appropriate length of the questionnaire, ten items with highest loadings were chosen in each factor. On the final questionnaire the response option of ‘not applicable’ was removed. The responses are calculated as points; never scores 100, rarely 75, sometimes 50, often 25 and always 0 points. HRQOL is reported by overall score and by two subscales. The scores are calculated by sum of the points divided by the sum of completed items. Low scores indicate low HRQOL. (Hatt et al., 2009a.)

The psychosocial subscale of AS-20 consists of items assessing body image, interaction and self-perception whereas the functional subscale has items on use of vision, difficulties with reading and general function and concerns of strabismus. AS-

20 has high internal consistency with good discriminative validity (Hatt et al., 2009a) and it has been shown to be responsive to change with good test-re-test ability (Hatt et al., 2010a; Leske et al., 2010). AS-20 shows strong correlation with Derriford Appearance Scale (DAS-59) which measures individual's distress of appearance. When strabismic adults score low, particularly on psychosocial subscale on AS-20 (low HRQOL), the scores on DAS-59 are high (greater distress of appearance). (Durnian et al., 2009.)

The developers conducted Rasch analysis to further analyse psychometric properties of the AS-20 and the results showed that four subscales of self-perception, interaction, reading function and general function would be more appropriate compared to previous two subscales. The response options in general function subscale were also reduced to four and one item each in reading function and in general function were removed. HRQOL scores can be calculated using the provided look-up table or computing the mean of all completed items separately for each subscale. The refined AS-20 is recommended for use as it may be more responsive to changes in HRQOL after treatment or time. (Leske et al., 2012.) AS-20 has been translated and validated into other languages and cultures and the validation processes vary (Akbari et al., 2015; Ali et al., 2015; Battista Marcon & Pittino, 2017; Burggraaf et al., 2021; Gothwal et al., 2015; Margotto et al., 2023; Ortiz Montero et al., 2023; Wang Z-H. et al., 2013; Yu et al., 2013). Both Chinese translated AS-20 and A&SQ were assessed to measure Chinese strabismic adults' HRQOL and the psychometric properties were comparable and satisfactory (Wang Z. et al., 2014). The Chinese AS-20 was further assessed by Rasch analysis and shown to be a rigorous measure to assess the HRQOL in Chinese strabismic adults (Wang Z. et al., 2015).

**The AS-20** is a patient-reported strabismus-specific HRQOL instrument which is shown to be more sensitive and responsive in measuring HRQOL in strabismic adults than VFQ-25 (Hatt et al., 2010a; Hatt et al., 2009b). Additionally, AS-20 measures vision-specific functional problems, which the A&SQ does not measure (van de Graaf et al., 2017). As AS-20 is shown to be reliable instrument for strabismic adults and measures also change in HRQOL after treatment, it was chosen as a HRQOL measure for this study.

**Table 1.** Condition-specific instruments on measuring HRQOL in strabismic adults

Properties	VFQ-25	A&SQ	AS-20
Developed in	the United States	the Netherlands	the United States
Number of items	25 items	26 items	the original 20 the refined 18
Domains	general health, general vision, near vision, distance vision, driving, peripheral vision, colour vision, ocular pain, vision specific role difficulties, vision specific dependency, vision specific social functioning and vision specific mental health	distance estimation, visual disorientation, fear of losing the better eye, diplopia, social contact and cosmetic problems	<b>the original:</b> psychosocial, functional <b>the refined:</b> self-perception, interaction, reading function and general function
Scale	varies by subscales, for example: definitely true, mostly true, mostly false or definitely false OR a little of, some of, most of and all of the time	varies by items, options in 5-point Likert scale: None, a little, some, most of and all of the time	5-point Likert scale of: never, rarely, sometimes, often and always The refined general function subscale 4-point Likert scale of: never/rarely, sometimes, often and always
HRQOL scores	Scores 0-100, higher scores indicate better HRQOL	Scores 0-100, higher scores indicate better HRQOL	Scores 0-100, higher scores indicate better HRQOL
Patient groups	patients with ophthalmic conditions	strabismic and amblyopic patients	strabismic patients, also used for adolescents
Language versions	several languages, not Finnish	several languages, not Finnish	several languages, now available in Finnish

## 2.4 Psychosocial support for adults with ophthalmic conditions or facial disfigurements

The literature showed adults with ophthalmic conditions or facial disfigurements have varied expectations and needs for psychosocial support. The studies also described the benefits of psychosocial support for these patient groups. It is important to note that severity or aetiology of facial disfigurements or ophthalmic conditions vary. Additionally, patients with ophthalmic diseases of macular degeneration or glaucoma are generally older adults and strabismic adults vary in age. Therefore, the literature search studies cannot directly be applied to strabismic adults. However, they can be used as a background for development of the psychosocial support together with strabismic adults.

The literature showed that the patients' psychosocial needs were not always met and the patients were eager to receive support (Breen et al., 2017; Williamson et al., 2023; Zhang M. et al., 2023). Psychosocial care were seen as an integral part of clinical practice for aiding holistic approach to care but not often seen demonstrated in ophthalmic clinical practice (Watkinson & Williamson, 2023). Nurses can act as vital advocates and leaders in co-ordinating multi-disciplinary team in providing psychosocial support and care and being involved in managing the follow-up care with diabetic retinopathy, glaucoma or plastic surgery patients (Gray et al., 2012; Valente, 2004; Zhang M. et al., 2023).

### *Social support*

Social support was important to patients for adjustment or coping with ophthalmic conditions or facial disfigurements. For patients with vision loss the social support was others helping with practical daily tasks or problematic situations (Kempen et al., 2012; Kumar et al., 2022). Adults with vision loss, inadequate social support and awareness of their impairment felt more depressed than the ones with adequate social support (Senra et al., 2013). Patients felt that they had to depend on others, although family members or paid staff could aid them to achieve active life and help them to look after themselves and their ocular condition (Hua et al., 2023; McGrath et al., 2017). Perceived social support was more important protector of mental health than visual acuity in patients with age-related macular degeneration and diabetic retinopathy (Hernandez-Moreno et al., 2021). Social support helped also with the adjustment to facial disfigurement (Borwick, 2011) and improved self-

esteem, body image and mental health in elderly with visual impairment (Horowitz et al., 2003; Kleinschmidt, 1999).

#### *Mental health support*

Emotional support from family members, friends and healthcare professionals aided patients with disfigurements or eye diseases to cope with anxiety, distress, fear, depression and surgical process (Hark et al., 2019; Valente, 2004; Zhang M. et al., 2023). Emotional support consisted of friendly interactions, physical touches, visits and ways to manage negative emotions (Hua et al., 2023; Kleinschmidt, 1999; Wu & Choy, 2023). Interventions for psychological support included meditation, music, hypnosis, stress reduction techniques, and discussions or counselling with healthcare professionals (Killeen et al., 2023; Pybis et al., 2016; Wu & Choy, 2023).

Cognitive behavioural therapy was utilised in supporting the patients with facial disfigurement and visual impairment by a self-help course, a leaflet or a referral to a specialist (Borwick, 2011; Newell & Clarke, 2000; van der Aa et al., 2015). Offering counselling was seen important by patients with partial or total sight loss, although they felt that the counsellor should be someone who understands what the loss of sight means to the patients (Thurston, 2010). Healthcare professionals reported that counselling would be important if the patients have unrealistic expectations of treatment, or generally for psychological support for both patients with facial disfigurements and eye diseases (Borwick, 2011; Estcourt et al., 2008; Hark et al., 2019; Pybis et al., 2016; Valente, 2004). It is important that professionals who provide counselling for anxiety in patients with ocular conditions, are aware of the patients' socio-economic status and consider it in discussions with them (Zhang X. et al., 2023).

#### *Informational support*

The results indicated that patients with ocular diseases and facial disfigurements require education and information on their health condition verbally and written, e.g. in patient leaflets (Borwick, 2011; Estcourt et al., 2008; Gray et al., 2012; Hua et al., 2023; Zhang M. et al., 2023). The patients with facial disfigurements expected that their care and outcomes of surgery or other treatments were explained to them the way that they could understand the care process (Valente, 2004).

It was important to also discuss the expectations the patients had for treatments. (Valente, 2004). Medicine education was utilised in intervention studies with glaucoma patients (Hark et al., 2019; Killeen et al., 2023). Patient education can ease the fears of illness and treatments. It is always important to consider the cultural

aspects in patient education, both in written material and interactions. (Valente, 2004.)

#### *Expectations for psychosocial support from healthcare professionals and services*

The literature showed that the healthcare professionals should have an understanding and compassion for older people and their subjective experiences, and focus on the patients rather than the required tests or prescription of medicines when caring for patients with vision loss or glaucoma (Hua et al., 2023; Kumar et al., 2022). Patients expected personalised care matching their individual needs and clear and targeted education without medical terminology (Hua et al., 2023; Kleinschmidt, 1999; Zhang X. et al., 2023). They also wanted to participate in the decision-making of their care and felt that using mobile technology would help with communication and health education (Hua et al., 2023).

Healthcare professionals should empower patients to demand psychological support (Bertelmann et al., 2016), although counselling and emotional support need to be already available in the care processes (Pybis et al., 2016). The support and continuity of care can be organised within multidisciplinary team so the patients would receive timely information, holistic care and support (Breen et al., 2017; Estcourt et al., 2008; Hark et al., 2019; Zhang M. et al., 2023). It is important there is support both before and after facial disfigurement surgery (Estcourt et al., 2008; Valente, 2004).

Professionals are encouraged to use developed interventions for glaucoma and visually impaired patients (Gray et al., 2012; Killeen et al., 2023; van der Aa et al., 2015), promote positive thinking and provide social skills training for the patients with facial disfigurements (Borwick, 2011; Valente, 2004). Both patients with facial disfigurements and ocular conditions need strategies to cope with their condition and the healthcare professionals can support the patients to find their own coping skills (Borwick, 2011; Breen et al., 2017; Estcourt et al., 2008; Zhang M. et al., 2023).

#### *Peers as psychosocial support*

Patients with glaucoma felt that peer support groups had helped them to understand the illness, receive information about the care and gave them hope for the treatment of the illness (Hua et al., 2023). Peer support was also seen helpful with adaptation to loss of vision and increasing of self-confidence (McGrath et al., 2017). For patients with facial disfigurement, meeting with peers was important to express their feelings and to know that they are not the only ones in the situation (Borwick, 2011).

Support groups can be helpful with some individuals with partial or total vision loss and not helpful for some others (Thurston, 2010). Face-to-face meetings might provoke painful experiences for some patients with facial disfigurement (Estcourt et al., 2008). As it is not known how the patient reacts to peer support, the professionals should encourage patients to attend and try the groups (Bertelmann et al., 2016).

## 2.5 Summary of literature review

The impact of strabismus on individual's health-related quality of life has been studied internationally, mainly in the fields of ophthalmology and orthoptics. The studies are mainly statistical studies, either with cross-sectional or longitudinal approach. There are few qualitative studies which assess the influence of strabismus, both on the functional and the psychosocial well-being. The HRQOL of participants have been mostly measured by A&SQ, AS-20 or VFQ-25.

Strabismus had a wide and varied impact on one's health-related quality of life. The adults had functional struggles with visual symptoms, pains and aches and decreased general functioning. Psychosocial influence of strabismus was common for adults who did not have diplopia and on top of difficulties in interactions and social situations, some struggled with anxiety and depression. The angle of strabismus (larger angle, larger visible deviation) does not necessarily manifest as lower HRQOL as some patients with very small angle (mild deviation) had lower HRQOL compared to others with larger angles. The effect of strabismus on one's appearance following difficulties with employment or social bias require increased awareness. Appearance-related issues were one of the reasons for corrective surgery which is the common treatment for strabismus. Surgery has been shown to improve functional and psychosocial HRQOL both on adults with and without diplopia. The change in HRQOL should be measured in a patient-reported outcome measure, such as AS-20. There are some patients with psychosocial influences of strabismus who do not report increased HRQOL after clinically successful surgery. Therefore, the previous research recommends assessing psychosocial well-being and developing support for these patients.

Literature review on psychosocial support showed that there are recently developed psychosocial support interventions in ocular conditions but not for strabismic adults. The review confirmed that psychosocial support for ophthalmic and facial disfigurement patients is needed and expected as informational, social,



mental health and peer support. Psychosocial support is recommended for adults with psychosocial impact of strabismus but based on this literature review and previous Cochrane review (MacKenzie et al., 2016), there are no studies which described what psychosocial support for strabismic adults should consist of. The developed support interventions for other ocular condition could be adapted to strabismic adults. However, it is important to remember that the influence of strabismus varies and, therefore, involving strabismic adults in development is crucial.

Strabismic adult patients' health-related quality of life or their expectations, if any, for psychosocial support has not been previously studied in Finnish context. The research evidence on strabismic adults' expectations for psychosocial support or content of support is also limited internationally. Therefore, this study aims to fill the knowledge gap by providing translated and adapted Finnish AS-20 to assess HRQOL, new knowledge on Finnish strabismic adult patients' HRQOL and psychosocial influences of the condition and recommendations for psychosocial support to strabismic adult patients.

### 3 PURPOSE AND THE AIM OF THE RESEARCH AND THE RESEARCH QUESTIONS

The overall purpose of this study was to describe and explain the health-related quality of life in strabismic adults and to provide recommendations for psychosocial support to strabismic adults. The study consisted of two phases and a summary and both phases had two sub-studies. The first phase consisted of sub-studies I and II and quantitative methodology was utilised. The second phase was a qualitative design and consisted of sub-studies III and IV. The first sub-study (I) aimed to translate and culturally adapt the AS-20 questionnaire into Finnish and evaluate the psychometric properties of the Finnish AS-20. The aim of the second sub-study (II) was to examine associations between HRQOL and socio-demographic, self-reported strabismus-related and orthoptic status factors in Finnish strabismic adults using the AS-20. The third sub-study (III) aimed to describe Finnish strabismic adults' experiences of psychosocial influences of strabismus and the fourth (IV) their expectations for psychosocial support. The aim of the summary was to synthesise and consolidate study findings into recommendations for psychosocial support to strabismic adults.

The main goals of this study were to increase knowledge of the influence of strabismus on HRQOL in the general public and multidisciplinary healthcare professionals in different healthcare environments, and to develop care, including psychosocial care to enhance HRQOL among strabismic adults.

The research questions of the study are:

1. How do Finnish strabismic adults assess the translation of the Finnish Adult Strabismus Questionnaire (AS-20) and what are the psychometric properties of three different AS-20 structures? (sub-study I)
2. What socio-demographic, self-reported strabismus-related and orthoptic status factors have associations with HRQOL of strabismic adults using the self-reported Finnish AS-20? (sub-study II)

3. How do Finnish strabismic adults describe their experiences of the psychosocial influences of strabismus? (sub-study III)
4. What kind of psychosocial support Finnish strabismic adults expect from healthcare professionals? (sub-study IV)
5. What recommendations could be given for psychosocial support to strabismic adults? (summary)

## 4 MATERIALS AND METHODS

### 4.1 Research designs

This study consisted of both quantitative cross-sectional (sub-studies I-II) and qualitative descriptive (sub-studies III-IV) research and a summary to achieve the purpose of the study. In the first sub-study the AS-20 measure to evaluate strabismic adults' HRQOL was translated into Finnish and its' psychometric properties were assessed to validate the measure in a pilot study.

The second sub-study evaluated Finnish strabismic adults' HRQOL on the Finnish AS-20 using the same data. Against the clinical experiences and expectations, the Finnish patients reported unexpectedly high scores on psychosocial HRQOL. Therefore, an interview study was conducted to describe strabismic adults' experiences on the psychosocial influences of strabismus and their expectations for psychosocial support from the healthcare professionals. These are presented in sub-studies III-IV. The summary presents recommendations for psychosocial support to strabismic adults. The design, setting, materials and methods of the study are presented in the Table 2.

### 4.2 Setting of the study

This study was conducted in collaboration with ophthalmology outpatient clinic at a university hospital in Finland. At the first year of the study, in 2019, there were 3400 appointments and nearly 350 strabismus surgeries. In 2022, post-Covid, there were over 3000 ambulatory appointments in the unit and 350 strabismus surgeries were performed by the strabismus surgeons. The multidisciplinary staff, including nurses, ophthalmologists, optometrists, and orthoptists recruited the patients to the sub-studies. Ward secretaries were actively advertising the studies and participation.

**Table 2.** Summary of the research design, setting, materials and methods

Sub-study	Design	Setting	Subject and sources	Data collection	Data analysis	Reported in
I	A quantitative cross-sectional study	Ophthalmology outpatient clinic, university hospital in Finland	137 Finnish speaking strabismic adult patients with no cognitive disabilities, heart or brain infarcts or other severe health concerns	Self-reported questionnaire of background and strabismus questions. Finnish AS-20. Collected from Dec 2019 to Dec 2020	Descriptive statistics, Cronbach alfa values, Spearman correlation coefficients, Confirmatory Factor Analysis,	Paper 1
II	A quantitative cross-sectional pilot study			Self-reported questionnaire of background and strabismus-related questions. Finnish AS-20. Orthoptic data from the electronic patient records collected from Feb 2020 to May 2021	Descriptive statistics, Cross-tabulation, Chi-square test, Mann-Whitney U, Kruskal-Wallis	Paper 2
III	A qualitative descriptive study		12 Finnish speaking strabismic adult patients with experiences of psychosocial influences of the condition	Individual semi-structured interviews conducted between August 2022 and February 2023	Inductive content analysis	Paper 3
IV	A qualitative descriptive study		Participants of sub-studies	Results of the sub-studies	Inductive content analysis	Paper 4
Summary	Synthesis of the results				Synthesis	Summary

### 4.3 Translation and psychometric properties of the Finnish AS-20, and the HRQOL in strabismic adults (sub-studies I-II)

The Adult Strabismus Questionnaire (AS-20) was used in sub-studies I and II to measure health-related quality of life. The English AS-20 (Hatt et al., 2009a; Leske et al., 2012) is in the public domain and available freely to translate and use so a permission was not required. However, the original developers were contacted regarding the intended translation to confirm that the measure is not already translated into Finnish and to understand the structure and scoring of the measure. Permission was asked and received for use of the four additional items of the 181 original items (Hatt et al., 2019a) to enhance the cultural aspects of the questionnaire for Finnish adults.

The translation followed the guidelines proposed by The Professional Society for Health Economics and Outcomes Research (Wild et al., 2005). Firstly, all items were forward translated into Finnish and the translation was assessed in the research group. Minor changes were made in language of one of the items and the first version of AS-20 was approved by the research group. Five Finnish speaking non-strabismic adults were then asked to comment the clarity and fluency of the Finnish translation and based on their comments, a few corrections were made to the grammar and wording. The corrections were discussed and approved in the research group and the translated measure sent to a professional interpreter for back translation. The research team compared the original English AS-20 measure and back translated measure and concluded that the meaning of the items was the same and the Finnish AS-20 was approved for testing.

#### 4.3.1 Instruments

The background questionnaire consisted of demographic and strabismus-related questions, such as sex, year of birth, highest education, perceived presence and visibility of strabismus and experienced diplopia (Mason et al., 2023, Table 1). The impact of strabismus on work or tiredness of the eyes were also enquired. Global Life Satisfaction was assessed by one item of the Finnish Satisfaction with Life Scale (SWLS), “I am satisfied with my life” (Backman & Hentinen, 2001; Diener et al.,

1985). The Finnish translation of the SWLS has a five-point Likert scale compared to the original English seven-point scale.

Psychometric properties of the original English AS-20 (Hatt et al., 2009a) were assessed and refined by Rasch analysis (Leske et al., 2012). The analysis revealed that rather than calculating a composite score and two subscale scores of patients' HRQOL, there should be four subscale scores and no composite score. Additionally, as the extra items were added to the original AS-20, the psychometric properties were assessed for three different structures for the Finnish AS-20: the original AS-20, the original AS-20 with Finnish additions and the refined AS-20.

The Finnish AS-20 had 24 items for the participants to assess and complete. 20 of the items were the same as the English AS-20 (Hatt et al., 2009a) and four items were collected from the original development of the AS-20 (Hatt et al., 2019a). All items had a five-point Likert style of never, rarely, sometimes, often and always. Participants were advised to circle one option which best reflected their situation regarding impact of strabismus on their well-being.

For the sub-study II, the orthoptic status variables of the participants were collected from the electronic patient records. These included the direction and angle of the deviation and binocularity both near and distance and the assessment of cyclodeviation. The deviation was measured by prism dioptres in near and far and categorised into five groups of esotropia (2-95 $\Delta$ ), exotropia (1-95 $\Delta$ ), vertical deviation (1-30 $\Delta$ ), esotropia and vertical deviation, exotropia and vertical deviation. Binocularity was evaluated by Bagolini® striated glasses and the findings were categorised into normal retinal correspondence (NRC), Suppression or Diplopia.

### 4.3.2 Participants and data collection

The participants for the sub-studies I and II were recruited from a Finnish university hospital's ophthalmology outpatient unit. The inclusion criteria consisted of 18 years or older, generally healthy Finnish speaking patients who did not have cognitive difficulties, thyroid eye disease or severe health conditions, such as brain or heart infarcts. Patients with other critical mental or physical health conditions were also excluded. Common eye diseases, for example cataract, were not criteria for exclusion. The sample size for validation studies of instruments is not universally accepted (Anthoine et al., 2014) and therefore the sample size was calculated following the rule five participants per item (Hair, 1998). For the Finnish AS-20, four additional items of the original development phase of the measure (Hatt et al., 2019a)

were included. For the 24 items the minimum sample size was calculated to be 120 participants and, therefore, 150 strabismic adults were purposefully recruited by the unit's multidisciplinary team to participate in the study. Participation was voluntary, did not affect the patients' care and they were informed they can withdraw from the study at any time. However, the information they shared could be used for the study as per ethical and research permissions. Written informed consent was collected. Participants filled both questionnaires independently either at home or at the waiting area of the unit. A postage paid envelope was included with the information leaflet in the study pack to aid the return of the questionnaires.

In total, 150 participants were recruited for the study and 138 returned the questionnaires with two reminders for participation. One of the participants who returned the questionnaires had a severe health condition and as a result the individual's data was excluded from the study. Therefore, the data of 137 participants was included in the sub-studies I and II. The data included both self-reported background questionnaire and Finnish AS-20 (sub-studies I-II) and the orthoptic status from the patient data system (sub-study II).

### 4.3.3 Analysis of the data

The participants' self-reported demographic and strabismus-related variables were described by frequencies and percentages for categorical variables and mean (M), standard deviation (SD), median (Md), quartiles (Q1, Q3) and minimum and maximum for the quantitative variables. The participants' year of birth was calculated as age on the day of the questionnaire completion and the age was categorised to protect anonymity. The categories were: 18–30, 31–44, 45–63 and 64–84 -year-olds. Data analysis was conducted using IBM SPSS Statistics version 25 and MPlus 8.5 for confirmatory factor analysis (CFA). Statistical significance was set at  $p < 0.05$ . (Duffy et al., 2005.)

#### **Assessment of psychometric properties (sub-study I)**

The psychometric properties of three structures of the Finnish AS-20 were evaluated assessing internal consistency, convergent validity and construct validity. Internal consistency evaluates how consistently all the instrument items measure the construct, in this case HRQOL. In this study, Cronbach alpha values were used to assess internal consistency. Values were calculated separately for all three structures of the Finnish AS-20 and the lowest value was set at 0.70. (Vet et al., 2011.)



Convergent validity describes how well the current instrument converges, relates to another instrument measuring the same construct (Vet et al., 2011). As there were no HRQOL instrument for strabismic adults in Finnish, Spearman correlation coefficients were calculated between one item of the Finnish SWLS “I am satisfied with my life” (Backman & Hentinen, 2001; Diener et al., 1985) and the subscale scores of three structures of AS-20 and the composite scores of AS-20 original and AS-20 original with Finnish additions. Values of 0.20–0.49 indicate low correlation, 0.50–0.69 moderate, 0.70–0.89 high and 0.90–1.00 very high correlation. (Munro, 2005a; Tabachnick & Fidell, 2014.)

Construct validity indicates how well the instrument evaluates the construct it is developed to measure (Vet et al., 2011). In this study, confirmatory factor analysis was chosen to assess the construct validity of the three AS-20 structures as the original English AS-20 and the refined AS-20 structures were known (Vet et al., 2011).

### **Associations between the HRQOL and demographic, self-reported strabismus-related and orthoptic status variables (sub-study II)**

The associations for the quantitative variables were assessed using non-parametric tests as the distribution of AS-20 scores were skewed. Mann-Whitney U test was selected for variables with two categories whereas Kruskal-Wallis test was chosen for the variables with three or more categories. Associations between binocularity and experienced diplopia were evaluated with cross-tabulation and Chi-square. (Munro, 2005b.) Refined AS-20 structure with 18 items and four subscales was used and the HRQOL scores were computed by calculating the mean of completed items (Leske et al., 2012).

## **4.4 Psychosocial influences of strabismus and expectations for psychosocial support (sub-studies III-IV)**

### **4.4.1 Participants and data collection**

The participants for the sub-studies III-IV were 12 Finnish-speaking strabismic adults who completed the Finnish AS-20 between August 2022 and February 2023. The inclusion criteria were 18 years or over adult patients with the ability to

communicate in Finnish who had experiences of the psychosocial influences of strabismus and had no severe mental or neurological illnesses. As the sub-studies III-IV aimed to understand the experiences and the expectations of patients with psychosocial influence of strabismus, participants had to have first-hand experience to be key informants. Therefore, the recruitment was purposeful aiming to reach the most informative patients. (Moser & Korstjens, 2017b.)

The patients were approached by the optometrists, orthoptists, or ophthalmologists at the clinic after reviewing the patients' AS-20 responses. The patients who responded sometimes, often or always on the AS-20 items measuring psychological and social dimensions on HRQOL (self-perception items 1-4, 6 and interaction items 5, 7-10) were offered participation. Total of 18 patients with visible strabismus were approached of which 13 agreed to participate and signed an informed consent statement. The remaining five declined participation for not having time to participate or not being interested in the study. One of the 13 consented patients did not respond to the several requests on email or phone for arranging interview. Therefore, total of 12 strabismic adults were interviewed. Participation was voluntary and did not alter the patient care.

Data were collected with semi-structured individual interviews by the doctoral researcher either face-to-face (n=8) on the unit or on Microsoft Teams (n=4) between August 2022 and February 2023. Interview guide was used to support the researcher for the interviews. The interview guide was based on previous literature, created jointly in the research group and edited according to comments by other doctoral researchers conducting semi-structured interviews. The audio of all the interviews was recorded and three participants allowed videorecording. Field notes and an interview diary were kept during the interview period. All the patients received an ID code which was used in the interview recordings. (Holloway & Galvin, 2017.)

The doctoral researcher started all the interviews with explaining the purpose, methods, and the aims of the study, clarifying the protection and confidentiality of the data and describing the meaning of the voluntary participation. Despite the participants had already signed the consent form, they were asked if they are participating voluntarily in the study. Participants were told that the results of the study can be used to improve strabismus services. The doctoral researcher shared that she has a nursing background and had become interested in the HRQOL of strabismic adults in her former role as a Nurse Manager in ophthalmology. She emphasised that although she had previously managed the clinic, she had not been involved in the clinical care of the strabismic adults and during the interviews she

was working as a full-time researcher. Participants were advised of the opportunity of seeing a psychologist specialised in ophthalmology if they felt the need.

The demographic background information collected were the sex of the participants and the age categorised as 18–30, 31–44, 45–63 and over 64-years-olds to maintain anonymity. Strabismus-related questions consisted of *have you got strabismus in one or both eyes, onset of strabismus, have you had previous strabismus surgeries and how many surgeries and how many previous visits this time have you had at the unit*. After the participants had answered the background questions, they were asked to describe first their experiences of psychological and social influences of strabismus on their HRQOL and well-being and second their expectations for psychological and social support from the healthcare professionals. Exploratory questions of *you mentioned earlier, can you tell me more, I understood you saying, did I understand that correctly and is there anything else you would like to tell me on this subject* were used for both open-ended questions to enhance the understanding and knowledge of the phenomena. (Holloway & Galvin, 2017.) Duration of the interviews were between 28 to 45 minutes. For the sub-study III, the data saturation was reached after 10 interviews, and two further interviews were completed to establish that the collected data provided information for the research questions. For the sub-study IV, the data saturated after 11 interviews. (Kyngäs, 2019b.)

#### 4.4.2 Analysis of the data

Inductive content analysis was used for analysis of the data as there were no previous studies to describe the psychosocial influences of strabismus in Finnish adults or their expectations for psychosocial support (Kyngäs, 2019a). Phases of data reduction, data grouping and formation of concepts, as recommended by Kyngäs (2019a) were followed. The audio recordings were transcribed precisely by the doctoral researcher and the transcriptions were reviewed by listening to the recordings to ensure the authenticity of the transcript. Latent content, such as interviewer observations of non-verbal communication during the interviews, was recorded to the transcribed text from field notes (Kyngäs, 2019a). The interviews produced 83 pages of transcribed text for both sub-studies III and IV. The analysis was conducted manually and separately for each sub-study.

First, the transcribed data was read several times. After familiarising with the data, the abstraction process began by collecting meaningful sentences, units of analysis, which answered to research questions from the transcribed text. The participants'

ID codes were included in the units of analysis to ensure that the original authentic quotations could be returned to and to check that understanding of the participants experiences was correct. Units of analysis were reduced into open codes where only the relevant information for research question was kept. The abstraction continued with choosing open codes describing similar experiences and grouping them together to form subcategories which were named accordingly. The related subcategories were then further abstracted to create categories. For the sub-study III the abstraction process continued to join categories together to form main categories. The sub-study IV results were abstracted to category level as the content of the categories were not similar and the abstraction process could not be continued further. (Kyngäs, 2019a.) Several units of analysis had more than one open code in both analyses. The field notes with latent content, such as “crying emotionally when talking about experiences in adolescence” strengthened the analysis which was discussed and reviewed in the research group at every stage. (Kyngäs, 2019a.) The units of analysis were translated into English for reporting of the results.

The research question of *how do Finnish strabismic adults describe the psychosocial influences of strabismus* guided the analysis for the sub-study III. With the research question in mind, the doctoral researcher chose units of analysis from the participants’ experiences which answered to the research question. The units of analysis were reduced to open codes and a total of 358 open codes were produced. The open codes were abstracted into 20 subcategories of which were further abstracted into four categories. Abstraction continued and the four categories were further abstracted to form two main categories.

For the fourth sub-study (IV) the above-described phases were repeated. The doctoral researcher focused on the research question of *what kind of psychosocial support Finnish strabismic adults expect from healthcare professionals*. A total of 187 open codes were reduced from the units of analysis and abstracted to create 15 subcategories, which were further abstracted into four categories.

## 4.5 Formulation of recommendations

The summary aims to describe the recommendations for psychosocial support to strabismic adults. Sub-study I provides a Finnish AS-20 measure to assess strabismic adults’ HRQOL in clinical practice. Using the AS-20 results both aids healthcare professionals to gain an understanding of impact of strabismus and provides a tool to approach patient’s general, functional and psychosocial well-being. Sub-study II

presented pilot results on Finnish strabismic adults' HRQOL. Both sub-study results were discussed with the research team and agreed that the findings supported a decision for a qualitative phase. The sub-study III showed that the participants struggled psychosocially from strabismus many ways. They also expressed the need for psychosocial support and described their expectations for the support in the sub-study IV.

Timing it Right framework was utilised in the formulation of recommendations. The framework was originally developed to support family caregivers' changing needs from hospital to home with their family member affected by stroke (Cameron & Gignac, 2008). The framework has been used in ophthalmic nursing with diabetic retinopathy patients to describe patient experiences of different phases of care process from hospital to home (Zhang M. et al., 2023). On this study, the phases of the proposed recommendations are based on the strabismic adult patients' different appointment types pre- and post-operatively in the university hospital's ophthalmology clinic. The process generally consists at least three visits before surgery: first visit, follow-up visit and pre-operative visit, and minimum of one visit after surgery. The Finnish Health Care Act defines that the patient must receive treatment within six months if their condition is not urgent (FINLEX, 2010). Strabismus surgery in the public healthcare falls under that regulation.

Synthesis of the results commenced with gathering all the sub-study results into one Microsoft Excel™ file. The overall results were read through carefully and assessed thoroughly with reflection. The doctoral researcher used questions, such as *what do these results mean for the psychosocial care of strabismic patients, when in the care process should psychosocial support be given, are there any socio-demographic factors that should be considered, what kind of support is already provided and what further support is needed.* The process continued with deductive reflection of the results to current clinical patient services and care pathways of strabismic patients. Timing it Right framework aided in the reflection process in visualising strabismic adult patients' care pathway in specialised healthcare. Previous literature shows that synthesis of research evidence can be used to make informed decisions, practice guidelines, recommendations and development of patient services which could potentially improve patients' health outcomes and quality of life (Buchholz & Dickins, 2023, 171–185; PCORI, 2024).

# 5 RESULTS

## 5.1 Characteristics of the participants

The participants for the sub-studies I and II were 137 adults who had sought help and were referred to the unit for treatment of strabismus. The age of the participants ranged from 18 to 84 years of age representing the patients of the unit. There were more women than men (59 % vs. 41 %) and nearly 80 % self-reported their strabismus as visible. Diplopia was recorded by over 60 % and over two-fifths (44 %) had at least one strabismus surgery in the past (Mason et al., 2023, Table 1).

The participants for the sub-studies III and IV consisted of 12 adult patients who had been referred to the strabismus services and who had experienced psychosocial influences of strabismus on their well-being. Of the participants eight were females and four males. Three adults had adult-onset strabismus, and two participants had no previous surgery. Table 3 describes the participants of the sub-studies III and IV.

**Table 3.** Participant characteristics of sub-studies III and IV

Variable	n
<b>Sex</b>	
Female	8
Male	4
<b>Age categorised</b>	
18–30	5
31–44	2
45–63	3
64–	2
<b>Previous surgery</b>	
0	2
1	5
2	3
3	2
<b>Onset of strabismus</b>	
childhood	9
adult	3

## 5.2 Translation and validation of the AS-20 into Finnish (sub-study I)

The translation of the Finnish AS-20 was commented as clear and understandable although the term “never” on items 5 and 19 was described double negative and a change for the wording was recommended. The participants used all response options of never, rarely, sometimes, often, and always, however, the option always was used the least. Participants requested more items on ocular symptoms, impact of driving and eye glass usage and psychosocial influence. Five patients recorded on the questionnaire their joy that the impact of strabismus is studied in Finnish context.

The participants reported lower functional (Md=53, Q1=38, Q3=66) than psychosocial (Md=75, Q1=54, Q3=90) HRQOL in the **original** AS-20 scoring. Whereas, in the **refined** AS-20 structure HRQOL scores in the interaction subscale were higher (Md=88, Q1=65, Q3=100) than the self-perception subscale (Md=60, Q1=38, Q3=85). The scoring method in the refined AS-20 was compared between the look-up table (Leske et al., 2012) and the original method of computing mean sum of completed items, and the scores were very similar in self-perception, interaction and reading function between the methods. Nevertheless, for the general function subscale, HRQOL scores were much lower with the original method compared to the look-up table.

Both the original AS-20 and the original with Finnish addition structures showed high internal consistency and reliability. Similarly, high Cronbach alpha was revealed in self-perception, interaction and reading function subscales of the refined AS-20. Whereas the value in general function subscale was borderline.

Convergent validity assessed by Spearman’s correlation coefficient between the item “I am satisfied with my life” and the overall scores of the original AS-20 and the AS-20 with Finnish additions, and the sum scales of self-perception and interaction subscales of the refined AS-20 showed moderate positive correlations. However, the score for reading function was very low.

Construct validity, assessed by CFA revealed that RMSEA values were higher than the recommended cut-off limit of 0.06 for all three structures and the chi-square goodness of fit showed statistically significant result suggesting no fit. The SRMR was satisfactory for the refined AS-20 (0.077). However, the CFI and TLI values were acceptable for all three structures. Table 4 presents the descriptive statistics, psychometric properties and model fit indicators of three Finnish AS-20 structures.

**Table 4.** Descriptive statistics, psychometric properties and model fit indicators of three Finnish AS-20 questionnaire structures and their subscales

	Median (Q1, Q3) <sup>§</sup>	Cronbach alfa $\alpha^†$	Spearman's r coefficient <sup>‡</sup>	p <sup>*</sup>	RMSEA	CFI	TLI	SRMR
AS-20 original (items 1-20)	63.8 (48.8, 72.5)	0.919	0.501	p<0.001	0.141	0.949	0.943	0.124
AS-20 original PS (items 1-10)	75.0 (63.8, 90.0)	0.953	0.459					
AS-20 original FU (items 11-20)	52.5 (37.5, 66.3)	0.871	0.318					
AS-20 with Finnish additions (items 1-24)	63.5 (52.0, 74.0)	0.923	0.474	p<0.001	0.129	0.939	0.932	0.121
Finnish addition items (items 21-24)	68.8 (50.0, 87.5)	0.858	0.142					
AS-20 refined subscales	Clinical uses <sup>§</sup> Look-up table			p<0.001	0.111	0.976	0.971	0.077
AS-20 refined SP (items 1-4,6)	60.0 (37.5, 85.0)	0.950	0.439					
AS-20 refined IN (items 5, 7-10)	87.5 (65, 100)	0.905	0.456					
AS20 refined RF (items 12-13,16, 20)	50.0 (37.5, 78.1)	0.900	0.194					
AS20 refined GF (items 11,15,17-18)	43.8 (34.4, 59.4)	0.675	0.344					

Q1=lower quartile, Q3=upper quartile, PS=psychosocial, FU=functional, SP=self-perception, IN=interaction, RF=reading function, GF=general function

<sup>†</sup> = N varies from 131 to 137

<sup>‡</sup> = Spearman correlation coefficient calculated with item "I am satisfied with my life" of Satisfaction of Life Scale

\* = p-value for the Chi-square goodness of fit

<sup>§</sup> = scores calculated by computing the mean of all completed items

RMSEA= The Root Mean Square Error of Approximation; CFI= Comparative Fit Index; TLI= Tucker-Lewis Index; SRMR= Standardized Root Mean Squared Residual.



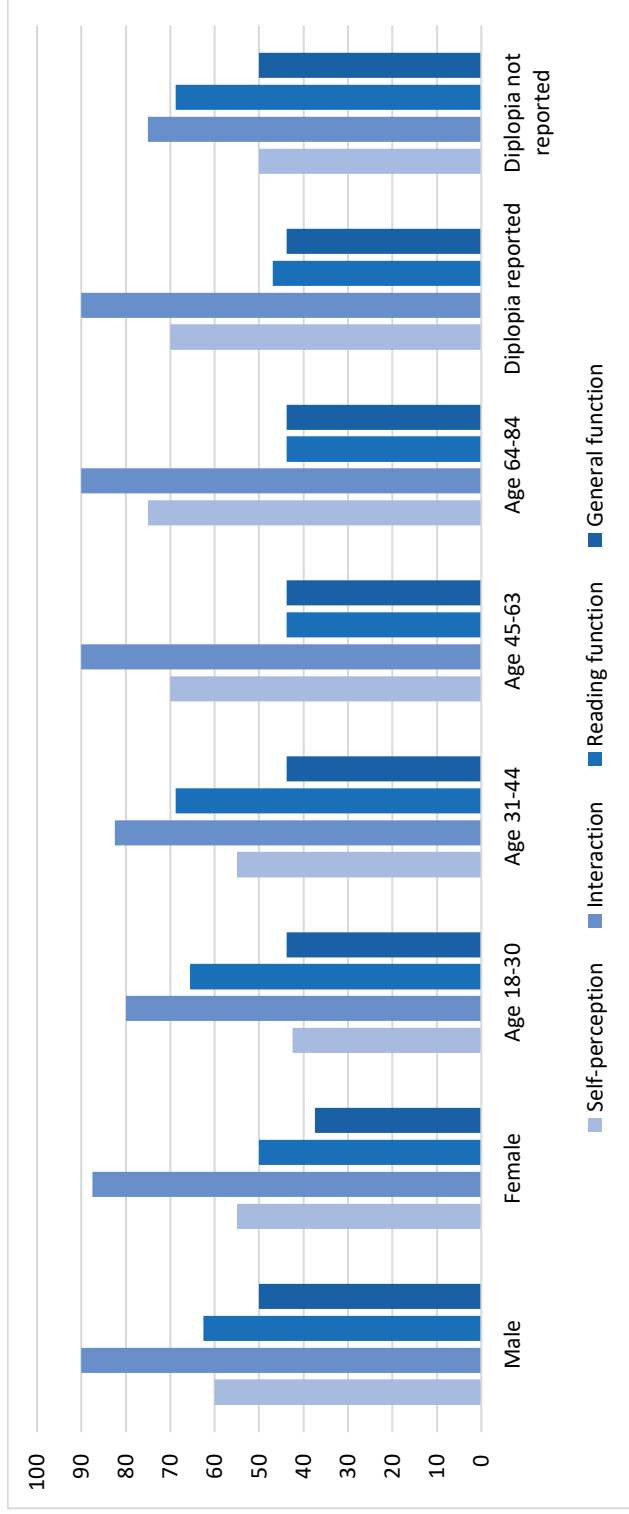
### 5.3 HRQOL in Finnish strabismic adults (sub-study II)

Participants reported both psychosocial and functional influences of strabismus. The associations between experienced diplopia and binocularity both in distance and near viewing showed that more people were self-reporting diplopia (63 %) than was diagnosed at the appointment (28 % for distance viewing and 27 % near viewing). The associations between the HRQOL scores and the participant characteristics showed that women had lower HRQOL than men in all four subscales. However, the difference in scores was statistically significant only in reading function ( $p=0.038$ ) and general function ( $p=0.001$ ) subscales. The age of the participants showed statistically significant association to self-perception ( $p=0.014$ ) and reading function ( $p=0.002$ ). The group of the youngest participants had lowest scores on self-perception and the two eldest age groups on reading function.

Participants' previous surgery had statistically significant association with lower scores both on self-perception ( $p=0.026$ ) and interaction ( $p=0.008$ ) subscales. Importantly, self-reported diplopia and the sum scores of all subscales had statistically significant association. Adults who self-reported diplopia had 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. Figure 4 presents participants' median AS-20 scores by the refined AS-20 subscales.

The most common types of strabismus were exotropia with or without vertical strabismus both on distance ( $n=54$ ,  $n=26$ , respectively) and near ( $n=46$ ,  $n=35$ , respectively) viewing. Although there were differences between the different strabismus groups, they were not statistically significant.

**Figure 3.** Participants' median AS-20 scores by the refined AS-20 subscales



## 5.4 Psychosocial influences of strabismus in Finnish adult patients (sub-study III)

The participants described experiences of challenges with social environments and struggles with mental well-being. Strabismus had caused stress in social situations, pressure in interactions and emotional and psychological burdens.

*Stress in social situations* was a regular experience and manifested in unpleasant experiences in social situations, people staring and general avoidance of social situations. Participants expressed discomfort when being photographed and increased pressure in their professional life.

Participants felt *pressure in interactions*. Hiding strabismus in interactions was common and the participants described several ways of doing it, such as, blinking or rubbing the strabismic eye, scratching head or standing in a particular way so the other people could not see the misaligned eye. Patients said that they avoid eye contact unless they know that the other person is aware of the eye condition. They were aware of their eye deviating and felt tense in interactions as they were concerned of others misjudging them. They had developed an awareness of others' gaze and behaviour during interactions, and this constant vigilance was mentally exhausting. They felt that strabismus had caused them to have struggles with intimate relationships and impacted their dating life.

Strabismus, its' treatment and symptoms had caused *emotional burdens*. Participants felt worried as they were not sure if strabismus would get worse or whether they could receive treatment for the misalignment. The constant symptoms of strabismus, such as eye fatigue or having to use several different glasses were irritating as the symptoms impacted the daily life and functioning. Participants also revealed negative emotions of feeling upset, shame and embarrassed. These emotions were present for example in social situations, such as work, or interactions with others.

Strabismus also led to *psychological burdens*. Participants described their struggles with self-confidence, both in adolescence and present day. As strabismus cannot always be corrected, the acceptance of oneself with misaligned eye felt difficult. Adults shared their experiences of being bullied in childhood and adolescence as well as adulthood and this had impacted their self-confidence. Participants communicated experiences of being different as they had often been the only ones with strabismus in their childhood school classes or social and professional circles in adolescence and adulthood. Appearance mattered, particularly to younger or female

participants, and they expressed that strabismus made them look less attractive and talked negatively of their appearance.

## 5.5 Strabismic adult patients' expectations of psychosocial support from healthcare professionals (sub-study IV)

Participants felt that psychosocial support needs to be offered to strabismic adults who have psychosocial influences of strabismus. They described that psychosocial support could consist of education of strabismus, genuine encounters with strabismus experts, accessible support and available peer support. They explained that the Finnish AS-20 with all the 24 questions described well their struggles with strabismus and should be used as part of the clinical practice.

Participants expected *education of strabismus*. They were happy with information and patient education they had received at the unit. Some of them explained that patient leaflets could have more medical knowledge, and the others highlighted that all information needs to be in understandable and clear language. They expressed that the public or their peers do not know enough of strabismus and keeping strabismus in the heart of public education would be needed. They had experienced difficulties accessing care and felt that generally healthcare professionals do not know of strabismus. Information on psychosocial influence of strabismus and the support provided would also be an integral part of education.

Participants reflected their appointments with strabismus experts and felt that the *encounters* had been *genuine*. They felt supported when the strabismus professional listened to them intently. They suggested that the professionals should bravely ask about psychosocial well-being and not get discouraged if they get told off. They expressed that open dialogue between the patient and the strabismus professional could also boost their self-esteem. They explained that it is important that the strabismus experts validate patients' symptoms and experiences, and to hear that others with the same condition have similar struggles.

Participants communicated their expectation for *accessible support*; this would mean timely support for children and adolescents when they need it, easy access to psychological care by nurses and psychologists and ongoing guidance on choosing a profession. Nurses or psychologists could provide psychological care to help with anxiety and stress. Participants also felt that they could benefit from having face-to-face practices for maintaining eye contact with the other people in interactive

situations. Support with choosing career was important for participants who had psychosocial impact of strabismus through their severe symptoms.

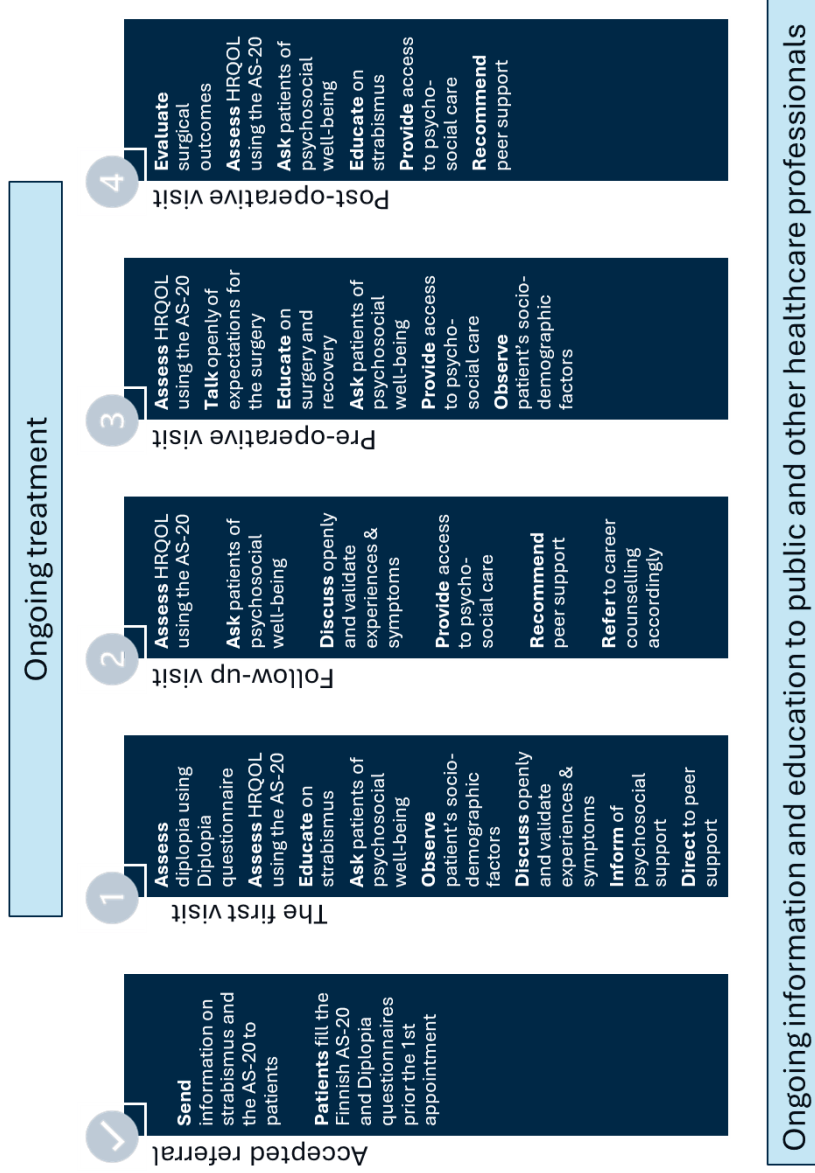
*Available peer support* was seen important for sharing information, experiences of treatments, emotions and difficulties on living with strabismus. They felt that peer support should be offered to varied age groups with different life situations and backgrounds to gain new perspectives to living with strabismus.

## 5.6 Recommendations for psychosocial support to strabismic adults (summary)

This study proposes recommendations for development of psychosocial support for strabismic adults. If psychosocial support intervention programme is developed in the organisation, it is imperative that strabismic adult patients and multidisciplinary team caring for patients are involved in development. As strabismic patients are generally cared for in the specialised healthcare, the focus should be on patients who are referred for treatment and who have psychosocial influences of strabismus. Most of the patients are treated with corrective surgery although surgery is not an option for all, the deviation might not be completely corrected, or even clinically successful surgery might not increase patient's HRQOL. Therefore, it is essential to provide support to strabismic adults in health care.

The proposed recommendations for supporting strabismic adult patients are shown in Figure 4 which is based on the "Timing it Right" framework (Cameron & Gignac, 2008). Knowledge of strabismic patients' appointments in clinical services aided composing of the framework.

Figure 4. Proposed recommendations for psychosocial support for strabismic adults, based on Timing it Right framework by Cameron & Gignac, 2008



Patients should continue to receive, as they already do, information on strabismus and the AS-20 prior their first appointment to have time to prepare for the appointment with the strabismus professional. Additional to the AS-20, patients would benefit self-assessing their diplopia prior the first visit with the Diplopia questionnaire (Holmes et al., 2005). On the first visit, it would be important that a professional evaluates the scores on both AS-20 and the Diplopia questionnaire, give patient education on strabismus and ask of their psychosocial well-being if responses on AS-20 indicate psychosocial struggles. It would be important to observe patient's socio-demographic factors, such as age and sex, as the sub-study II showed that women had lower scores on AS-20 in comparison to men, although significantly lower only on reading function and general function. Patient' age might impact HRQOL as sub-study II showed that younger patients had lower self-perception than the older participants. In observing the age, the professional can also notice children and adolescents and the need for timely support for these age groups if they struggle with psychosocial influences of strabismus as recommended in sub-study IV. As the professional discusses openly with the patient, they can also validate the symptoms and struggles the patient has. The first visit might be a good opportunity to talk about the available psychosocial support and direct the patient towards peer support.

Patients generally come for follow-up visits as they wait for corrective surgery. Patients' HRQOL needs to be discussed and if the scores indicate, also psychosocial well-being approached. If the patients have continuous burden in their psychological health, they will benefit of the psychosocial care. If the patients have strong adverse functional impacts of strabismus, it might cause them psychosocial issues or difficulties in their career. Therefore, career counselling services might need to be involved. Additional to current clinical practice of discussing the expectations of and educating on surgery, the pre-operative visit is a good place to enquire of psychosocial well-being and refer for psychosocial care accordingly. Psychosocial well-being and HRQOL should also be assessed on the post-operative visit and support continued accordingly. It is important that peer support continues, and the patient could support others after their treatment or corrective surgery.

## 6 DISCUSSION

### 6.1 Overview of the findings

#### 6.1.1 Translation and validation of the AS-20 into Finnish (sub-study I)

Sub-study I aimed to translate and culturally adapt AS-20 questionnaire into Finnish and evaluate the psychometric properties of the Finnish AS-20. The translation and adaptation followed recommended guidelines (Wild et al., 2005). Additionally, the doctoral researcher consulted the developers of the original AS-20 to understand the development process, the scoring and the clinical use of the measure to maintain the Finnish AS-20 close to the original (Vet et al., 2011). However, to consider cultural adaptation (Vet et al., 2011; Wild et al., 2005), additional items from the original development data were seen essential for the Finnish AS-20 (Hatt et al., 2019a). Purposive sampling of the participants ensured the participants reflected the target population for the aims of the sub-study (Vet et al., 2011).

Participants' comments on the language were noted and the measure changed accordingly (Wild et al., 2005). Patients' comments on more items on symptoms were considered and noted also in other translations (Ali et al., 2015; Yu et al., 2013). However, the decision was to keep the measure close to the original instrument, measuring the impact of strabismus on HRQOL and therefore no further items on symptoms were added (Hatt et al., 2009a; Vet et al., 2011).

Against the clinical experience, participants reported their psychosocial HRQOL higher than functional HRQOL. This could be due to sampling. In future, participants should be recruited based also on their diplopia status as the diplopic adults tend to have more functional struggles compared to non-diplopic adults (Buffenn, 2021).

Psychometric properties assessed were internal consistency by Cronbach alpha values, convergent validity by Spearman's correlation coefficients and construct validity by confirmatory factor analysis. The properties were assessed in all three AS-20 structures and their subscales. Based on the results, all structures were internally



consistent as shown in previous results of the original AS-20 development and Chinese and Danish translation (Ali et al., 2015; Hatt et al., 2009a; Yu et al., 2013). However, general function subscale of the refined AS-20 was slightly below recommended cut-off value of 0.70 (Vet et al., 2011). Similar result was reported by Leske et al. (2012). Spearman's correlation coefficient between "I am satisfied with my life" from the SWLS measure and all sum scales of Finnish AS-20 structures showed very low to moderate positive correlations. There were not previously translated HRQOL measures for strabismic or ophthalmic patients and therefore an item from SWLS was chosen. In future validation studies, 15D<sup>©</sup> Health-related quality of life instrument could be used for assessing convergent validity (Sintonen, 2001). The 15D<sup>©</sup> is validated and commonly used in the Finnish healthcare and many healthcare organisations have adopted it in the recent years.

Confirmatory factor analysis was used to assess construct validity. The sample size was slightly small but met the recommended values (Aroian & Norris, 2005). The chi-square goodness of fit showed statistically significant result suggesting no fit to any of the structures and the subscales. Small sample size might have impacted the chi-square values (Tabachnick & Fidell, 2014, 770). It is recommended to focus on a combination of SRMR and CFI values to minimise error rates in studies under 250 participants (Hu & Bentler, 1999) and based on the combination of these two values, the refined AS-20 showed the most acceptable construct validity. Based on the results, the refined AS-20 is the most satisfactory structure for Finnish AS-20 as recommended also by Leske et al. (2012). Further validation is required.

### 6.1.2 HRQOL in Finnish strabismic adults (sub-study II)

Sub-study II described and explained the HRQOL of Finnish strabismic adults. Participants' orthoptic status was collected from the patient data system among previously collected background and AS-20 data.

Participants had both psychosocial and functional impact on their HRQOL similarly to previous studies (Adams et al., 2016; Hatt et al., 2007; McBain et al., 2014a). Participants self-reported experiences of diplopia more often than diagnosed in clinical examinations. This result brought discussion of methods for diplopia assessment and translating and utilising Diplopia questionnaire in clinical practice (Holmes et al., 2005).

The current study showed that women had lower HRQOL than men and this is seen also in previous studies (Durnian et al., 2010; Sah, 2017; Wang Z. et al., 2018). However, our results showed statistically significant results only in reading and general functions. It is noteworthy that although there is no difference in prevalence of strabismus between females and males, females seek help for their condition more than men (Laughton et al., 2023). Could females also assess their HRQOL more thoroughly explaining the difference between sexes? As expected, the youngest age participants had lowest scores on self-perception which might relate to appearance-related and self-esteem concerns of young people. Appearance, cosmetic issues and improvement of self-esteem have been reasons for young adults to seek surgery in previous studies (Al-Omari et al., 2022; Paduca et al., 2021). Importantly, the current study showed that adults without self-reported diplopia reported statistically significantly lower HRQOL in self-perception and interaction than the adults with self-reported diplopia. Previous results report similar results (Hatt et al., 2009b; McBain et al., 2014b). This result is important in the context of publicly funded healthcare systems as there have been restrictions for surgeries for adults without diplopia (Arblaster et al., 2024b; El Meshad et al., 2024). The psychosocial impact of strabismus and the effect of surgery to HRQOL need further studying. As the participants were recruited purposefully based on the translation and validation purposes, the groups based on the type or angle of strabismus were not equal and this needs to be addressed in future studies.

### 6.1.3 Psychosocial influences of strabismus in Finnish adult patients (sub-study III)

The sub-study III described, for the first time in Finnish context, psychosocial influences of strabismus on adult patients who sought help for their condition. The participants described both challenges with social environments and struggles with mental well-being showing as stress in social situations, pressure in interactions and emotional and psychological burdens. Psychosocial influences of strabismus have not been widely studied previously using qualitative descriptive design.

Stressful social situations were common, and participants avoided some of them if possible. Situations where they were being photographed caused discomfort as strabismus is visible in photographs. Similar results are reported previously in mixed methods study (Wang Z et al., 2018). Participants explained and showed practical ways of hiding strabismus in many ways so others could not see the deviation. Hiding

strabismus could result from earlier unpleasant social experiences (MacKenzie et al., 2016). Others might interpret asymmetrical eyes as person being impolite or unfriendly (Wang Z. et al., 2018) and therefore hiding strabismus and avoiding eye contact could be explained. Misjudgement by others in interactions was described by the patients, they felt tense, were aware of others gaze and behaviour. Previous study reports the effect of strabismus surgery on public consciousness which is the indication of how a person believes others perceives them. It showed that strabismic adults suffer from public consciousness and surgical intervention reduced suffering. (Estes et al., 2020.) The influence of strabismus on intimate relationships and dating life was also shown in previous studies and reasons for seeking corrective surgery (Al-Omari et al., 2022; Paduca et al., 2021; Wang Z. et al., 2018).

Emotional burdens with worries about the treatment or access to the treatment was described by the participating patients. The worries can be reduced by providing education to healthcare professionals. Negative emotions such as, shame, feeling upset and embarrassed, were expressed by the participating patients strengthening the previous results by Wang Z. et al. (2018).

Strabismus also caused psychological burdens for the participants. They had low self-confidence, which is shown to be one of the reasons for seeking treatment (Paduca et al., 2021). Bullying due to strabismus was shared by the participants and they felt it had caused psychological implications. Previous studies describe bullying as common among strabismic children and adults (Buffenn, 2021; Wang Z. et al., 2018). Altered appearance due to strabismus was difficult particularly for female and younger participants in this study as in Wang Z. et al. (2018).

#### **6.1.4 Strabismic adult patients' expectations of psychosocial support from healthcare professionals (sub-study IV)**

The fourth sub-study aimed to describe strabismic adults' expectations of psychosocial support from healthcare professionals. The strabismic adults' expectations for psychosocial support have not been previously reported in Finnish or international context although patients' expectations for corrective strabismus surgery or perspectives on the outcomes from the surgery have been studied (Arblaster et al., 2024b; McBain et al., 2016b). Psychosocial care for patients with ocular conditions is limited (Watkinson & Williamson, 2023) and pre-operative psychological support or psychosocial interventions for strabismic adults are needed (Ehlers et al., 2023; MacKenzie et al., 2016). This study results can give an insight

from strabismic adults into the expectations of psychosocial support and what it could consist of.

Patients described the importance of education of strabismus. Informational support with understandable and clear language were highlighted also in recent studies of patients with other ocular conditions (Hua et al., 2023; Kumar et al., 2022). Intensive patient education can also improve patient-centred care in ophthalmology (Chow et al., 2022). Increased public education can increase societal awareness of strabismus and thus supporting psychosocial well-being and access to care for the participants of this study. Previous studies stated that increased public awareness reduces the delay in seeking treatment for the condition (Al-Omari et al., 2022; Paduca et al., 2021). When healthcare professionals in general are educated and aware of strabismus, its' influences and treatments, they are more likely to refer patients for treatment (Al-Omari et al., 2022; Buffenn, 2021; Paduca et al., 2021).

Genuine encounters with strabismus experts at the appointments was expected by the participants as part of psychosocial support. They felt that the professionals could bravely ask of their psychosocial well-being, discuss openly, validate their experiences and listen to them intently. Asking of psychosocial influences of strabismus and gathering information on patients' emotional well-being might impact the way professional communicates with the patient and eases referrals for further support (Naufal et al., 2021).

The participants expected accessible support with easy access to psychological care given by nurses and psychologists, timely also for children and adolescents and ongoing guidance for career and education. Psychological burden of strabismus in among children needs to be highlighted and appropriate support provided (Huang & Pineles, 2023). Psychological nursing could be useful as it has improved post-operative well-being among glaucoma operated patients (Chang M. et al., 2021). Peer support was noted as one of the methods for providing psychosocial support by the participants of this study. The participating patients emphasised that it is not the strabismus professionals' duty to organise the peer support but guide the patients towards the right direction. However, talking about the condition and the experiences of treatment would support others living with strabismus as reported in a previous study among patients with glaucoma (Hua et al., 2023).

### 6.1.5 Recommendations for psychosocial support to strabismic adults (summary)

Literature review and the sub-studies of this study indicated that strabismic adults with psychosocial influence of strabismus would benefit from psychosocial or psychological support (Ehlers et al., 2023; MacKenzie et al., 2016; McBain et al., 2016a; McBain et al., 2014a). Based on the literature review and communication with researchers in the USA and UK, psychosocial support intervention for strabismic adults has not been developed. Additionally, the evidence-based knowledge of the content of the support for strabismic adults is limited. The research evidence of sub-studies I-IV was synthesised and consolidated to formulate recommendations for psychosocial support to strabismic adults. The recommendations were produced deductively with previous clinical understanding of the healthcare services locally and nationally. Combining research evidence with knowledge of clinical experience and understanding the local context are seen as types of evidence in the delivery and development of patient care (Rycroft-Malone et al., 2004). Although recommendations are theoretical, discussions with multidisciplinary staff at the clinic can aid with validation of these recommendations.

Some of these recommendations have been part of the clinical practice prior this study and some of them, such as AS-20 and Diplopia questionnaires (Hatt et al., 2009a; Holmes et al., 2005), have been adopted as part of the practice during this study. The research collaboration with clinical psychologist has also opened doors for clinical consultations regarding strabismic adults' well-being. In the future, accessible and appropriate psychosocial care needs to be discussed and developed. The inclusion of clinical psychologists in multidisciplinary case meetings could also support strabismic patients' care.

It is important to stay realistic on the resources and aim of the publicly funded healthcare when thinking of psychosocial support intervention development. Understanding how many patients have psychosocial struggles and could benefit a structured support intervention, would be needed prior decisions on intervention development. If the group of the patients is small, it could be more efficient to focus providing psychosocial care individually rather than setting multidisciplinary resources on intervention development. It is also important to follow the patients with psychosocial struggles post-operatively to understand whether the struggles continue after surgery (McBain et al., 2014a).

Currently, there are no patient support groups for strabismic patients in Finland and the patients described their need for peer support. Strabismic adult patients can

be involved in the organisation's customer panels or volunteering. It could also be possible to use the knowledge produced in this study as a kick-start for patients to develop peer support. Strabismic patients could be invited to a presentation and discussion of the study results and potential actions for the creation of peer support could follow.

## 6.2 Ethical considerations

This study followed the Tenets of Helsinki Declaration (WMA, 2013), the Finnish and the European Code of Conduct for Research Integrity (ALLEA, 2023; TENK, 2023). The research principles of reliability, honesty, respect, and accountability were observed through the whole research process (ALLEA, 2023; TENK, 2023). Ethical recommendations and research permissions were acquired separately from the university hospital's Medical Research Ethics Board (3008/2019 and 3264/2021) and the department responsible for research in ophthalmology for both quantitative (sub-studies I-II) and qualitative phases (sub-studies III-IV) of the study.

The design of the study was considered carefully in the beginning of the research process and assessed during the process to maintain reliability of the study. The supervisors have been involved and consulted in decision-making of the study. The use of the unit's multiprofessional staff as recruiters for the study participants was discussed with management beforehand and the use of the resource was described in the Ethical Board and Research Permission application. The doctoral researcher has conducted the study on her own time, and it has not been part of her professional paid work. (ALLEA, 2023; TENK, 2023.)

Honesty has been guiding the research stages. The doctoral researcher has aimed to plan, conduct and report each stage transparently and fairly. Respect has been shown to other researchers by referencing their work correctly and the roles of the research team in publications have always been agreed on. The doctoral researcher has acted accountable, reported financial support, considered ethical matters through the research process and followed the Ethical Board recommendation, research permission and organisational policies at all times. (ALLEA, 2023; TENK, 2023). The quality of the study has been considered at all phases of the research by assessing both validity and reliability of the quantitative and trustworthiness of the qualitative sub-studies (Elo et al., 2014; Vet et al., 2011).

All participating patients received verbal and written information and they were given time to consider the possibility of participating before signing the informed

consent forms (Scott, 2013). The multidisciplinary team at the unit recruited the patients for both phases and the doctoral researcher was not involved in the recruitment. This was arranged to ensure that patients would not feel pressurised to participate. The recruiting professional emphasised that participation was voluntary and would not alter their care in the unit. The patients were also told of the possibility of stopping their participation or withdrawing from the study. However, the information obtained by that stage could be used in the study as per ethical recommendation and research permission. (Holloway & Galvin, 2017.) To stop participation or withdrawing from the study was enabled by contacting the doctoral researcher and her details were written in the information leaflet.

Participant confidentiality and anonymity was maintained through the study. All contact and communication with the patients, for example reminders of unreturned questionnaires, were respectful. Only the orthoptic status variables in sub-study II were collected from the electronic patient records and no other patient information was accessed. The face-to-face interviews were arranged in the unit's soundproof appointment rooms and the online interviews were organised that there were no other people in the room with the doctoral researcher during the interview. During the interviews the participants were given time and space to gather their thoughts and composure when they felt emotional. (McGrath et al., 2019; Scott, 2013.) The doctoral researcher was aware that the interview might be emotional to some participants and therefore all participants were informed that they have a right for a visit with the psychologist in the Ophthalmology Department.

Consent forms, completed questionnaires, and the electronic data were stored safely according to the organisation's research permission and research data guidelines. Anonymity and confidentiality were maintained by using ID codes in all saved data and reporting the results. Ages of the participants were categorised for the same reason. Only the doctoral researcher had access to the research data, but members of the research group had right according to the ethical recommendations and research permissions to see the anonymised data with the doctoral researcher. The data is not shared due to the research permission and therefore stored only in an organisation's secure password protected database with access by the doctoral researcher. The research data will be deleted according to the organisation's data guidelines and good research principles after archiving it for maximum of 15 years (TENK, 2023).

### 6.3 Strengths and limitations of quantitative sub-studies I-II

Reliability of quantitative studies can be evaluated by assessing research validity and reliability. Validity assesses if the study measures the phenomenon of interest it was designed to measure, and it can be evaluated internally and externally. Internal validity considers the accuracy of the research findings and external validity refers to the generalisability of the research, that is, if the results may be safely used in other settings than where the research originally took place. Reliability of the study focuses on the degree to which the study would produce similar results if the study was re-conducted. (Pierce, 2013; Vet et al., 2011.) In the following paragraphs the doctoral researcher reflects how validity and reliability were ensured at different stages of the quantitative sub-studies I-II.

#### *Validity and reliability of the study design and instrument translation*

The design of the sub-studies I-II was planned based on methodological literature (Hair, 1998; Munro, 2005b; Tabachnick & Fidell, 2014; Vet et al., 2011) together with the research group. Having an experienced ophthalmologist specialised in strabismus as part of the research group was essential for the study to give insight and understanding to the care of strabismic adults. The doctoral researcher aimed herself at being objective, aware of and avoid biases through all research process.

The background questionnaire was based on the previous studies and clinical experience of caring for strabismic patients. The questionnaire was created with the ophthalmologist, reviewed by the supervisors and statistician, and edited accordingly. Adult Strabismus Questionnaire (AS-20) was chosen for a measure to be translated, validated and piloted in Finnish context as it is a patient-reported outcome measure and based on the experiences of strabismic patients (Hatt et al., 2009a). The AS-20 is also shown to be responsive to change and, therefore, a good instrument to assess the impact of clinical care of strabismus (Hatt et al., 2010a; Leske et al., 2010). The translation process followed the guidelines for translation and cultural adaptation process by ISPOR task force (Wild et al., 2005). Cultural adaptation was observed by choosing additional items, Finnish additions, from the published original development data together with strabismus specialists (Hatt et al. 2019a). The required sample size was assessed by 5 participants for an item and, therefore, 150 participants were recruited to consider potential dropouts (Hair, 1998). These enhanced the validity and reliability of the sub-studies' design. The AS-20 has been translated and validated in other languages such as Dutch, Portuguese and Columbian Spanish (Burggraaf et al., 2021; Margotto et al., 2023; Ortiz Montero et



al., 2023) but the previous studies have not utilised the AS-20 development data items to enhance cultural adaptation which can be seen as a strength of this study (Wild et al., 2005).

#### *Validity and reliability of data collection*

The instruments used for the sub-study I were AS-20 and a background questionnaire. The sub-study II used the same data collected than sub-study I and additionally patients' orthoptic data was collected from the electronic patient data system. The multiprofessional staff at the unit recruited the participants for the study. The inclusion and exclusion criteria were written for validation as easy-to-follow guidelines for the staff. To support the recruitment the ophthalmologist and doctoral researcher went through the patients booked or waiting for appointments and marked the potential participants for the study. Additionally, all the clinicians were advised to consider participation when reviewing new referrals. It is possible this has created selection bias in where only the marked potential participants were recruited and some potential participants were not approached (Williams et al., 2021, 79–102)

Most of the data collection took place over Covid pandemic and it was a challenge for the research as many of the elective services were decreased and the patients could not receive appointments, or they were too scared to attend their outpatient visits. Additionally, the doctoral researcher was not able to attend the unit regularly to support data collection as she was working for the hospital's Covid services. Recruitment during the pandemic months might have created non-coverage bias as the potential participants might have not been reached to participate due to cancelled appointments or fear to attend (Williams et al., 2021, 53–78). Despite several reminders by text messages for returning of the questionnaires, some consented participants did not return them. This can be seen as non-response bias and, therefore, a possible limitation to the study (Williams et al., 2021, 53–78).

During data collection it was noted that the background question regarding the impact of strabismus on work were not valid for people who were retired, students or absent from work. This can impact the results and therefore be limitation for the study.

#### *Validity and reliability of data analysis*

The statistical tests were chosen based on methodological literature (Hair, 1998; Munro, 2005b; Tabachnick & Fidell, 2014; Vet et al., 2011) and confirmed with the statistician to enhance validity and reliability. Doctoral researcher conducted analyses

independently with support of the statistician, supervisors and the rest of the research team to ensure the diligence of the analyses and the reliability of the results. The analyses were checked and discussed together in the research team.

The assessment of psychometric properties (sub-study I) for the Finnish AS-20 were conducted for three different structures of AS-20: the original AS-20 with 20 items in two subscales, the original with Finnish additional items (24 items) and the refined AS-20 with 18 items in four subscales. The doctoral researcher and the research group concluded that it is significant to assess different AS-20 structures and the measure scoring options to establish which structure would be the most suitable for clinical and research use for evaluating HRQOL of strabismic adults in Finland. As the structure of the original and the refined AS-20 were known, confirmatory factor analysis was chosen for assessing construct validity (Vet et al., 2011). Conducting CFA enhanced construct validity of the Finnish AS-20.

The sub-study II evaluated the associations between the HRQOL and background demographic, strabismus-related and orthoptic status variables. The data was skewed and, therefore, non-parametric tests were utilised (Comiskey & Dempsey, 2013; Munro, 2005b). The sub-study II used the same questionnaire data which was collected from the participants for the translation and validation purposes of the AS-20. Therefore, it was not possible to analyse the associations between the adults' HRQOL and the different strabismus groups such as exotropic or esotropic patients.

#### *Validity and reliability of the results*

The translated AS-20 was accepted by the participants and some small suggestions were recommended for the language, for example double negativity in items, which were corrected in the translation. The participants commented that the Finnish additional items were important and, therefore, they were left in to improve the clinical purposes of the measure (Vet et al., 2011). The participants were a select group of patients from the unit; however, the sample provided a good representation of the units' patients based on age and sex. The unit cares for patients from all over Finland and for many of them Finnish is not their mother tongue. Inclusion criteria did not require Finnish as a mother tongue but ability to speak fluently and understand Finnish was required.

The assessment of the psychometric properties showed the refined AS-20 with 18 items in four subscales (self-perception, interaction, reading function and general function) to be most suitable for the research purposes. The comparison of HRQOL score calculations showed that the scores need to be calculated for Finnish strabismic

patients as mean sums of completed items rather than using the look-up table. (Hatt et al., 2009a; Leske et al., 2012). In the look-up table, the scoring combines the response options of never and rarely in general function subscale. The Finnish participants used all response options and, therefore, using the look up table for scoring showed much higher HRQOL in general function for Finnish strabismic adults compared to the computing of the mean of completed items. The validation process of AS-20 should continue in this population.

The sub-study II used the same collected data than the sub-study I and the patients were recruited for the AS-20 validation purposes. Therefore, the cohorts for deviation (esotropia group or exotropia group) were not the same size or large enough to conduct thorough analysis and comparison between the cohorts as previous studies have done (Sah, 2017; Thuma et al., 2023). Additionally, the changes in AS-20 language recommended by the participants were not introduced yet. These factors could have impacted the results of the sub-study II. Clear inclusion and exclusion criteria, clear descriptions of sample, statistical methods and analysis increase the external validity of the results (Pierce, 2013). These results can be generalised to other Finnish speaking strabismic adult patients, although it is important to note that strabismic patients with critical health conditions, cognitive difficulties or thyroid eye disease or patients not fluent in Finnish were excluded in this study.

It is important to remember that both sub-studies I and II are cross-sectional and evaluate the associations between the variables at one time. Therefore, no causality between the variables can be assumed.

## 6.4 Trustworthiness of qualitative sub-studies III-IV

Trustworthiness of qualitative sub-studies III and IV can be assessed using the criteria of credibility, dependability, confirmability, transferability (Cypress, 2017; Elo et al., 2014; Korstjens & Moser, 2018) and authenticity (Elo et al., 2014). Additionally, the principle of reflexivity is seen as essential in qualitative study (Cypress, 2017; Korstjens & Moser, 2018). In credible study, the research findings represent the participants, their thoughts, and experiences and the participants are described accurately (Elo et al., 2014; Korstjens & Moser, 2018). Dependability in qualitative study indicates that the data and the findings are stable and consistent over time (Cypress, 2017; Elo et al., 2014; Korstjens & Moser, 2018). Confirmability reflects the objectivity of the study and neutrality of the researcher, whereas

transferability refers to the extent how well the qualitative study findings can be generalised to other contexts or respondents (Elo et al., 2014; Korstjens & Moser, 2018). Authentic study shows many different realities rather than simplified results (Elo et al., 2014). Reflexivity helps researchers to critically self-reflect their potential biases and preferences to ensure the transparency of the qualitative study (Cypress, 2017; Korstjens & Moser, 2018). The next paragraphs will assess trustworthiness in sub-studies III and IV through these criteria.

### *Credibility*

The design of sub-studies III and IV was based on the results of sub-studies I and II in where it was noted that the scores of AS-20 psychosocial, particularly interaction subscale, were the highest of all AS-20 scores indicating high HRQOL. This result was opposite to the expectation of the research team and against the clinical experience of the strabismus specialists. The results raised questions how would Finnish strabismic adults describe the psychosocial influences of strabismus. Additionally previous research had stated that psychosocial support is necessary for strabismic adults (Ehlers et al., 2023; Hatt et al., 2018; MacKenzie et al., 2016; McBain et al., 2016a; 2016b) although it was not clear what psychosocial support should consist of. The doctoral researcher was in contact with both the UK and USA researchers who had studied the impact of strabismus and neither group had developed psychosocial support intervention. Therefore, sub-study IV was designed to describe Finnish strabismic adults' expectations for psychosocial support. Clinical psychologist specialised in ophthalmology was invited to the research team to provide her professional experiences for these sub-studies. All these strengthen the credibility of sub-studies III and IV.

Qualitative method as a study design enables holistic approach, exploration and understanding of the patients' experiences (Holloway & Galvin, 2017; Kyngäs, 2019b; McGrath et al., 2019; Moser & Korstjens, 2017a) and the descriptive design acknowledges the participants' experiences and different aspects of the phenomenon (Bradshaw et al., 2017). Semi-structured interviews with interview guide were used as data collection method as it allowed both flexibility in the interview situation and enabled structure for the interview and discussion (Qu & Dumay, 2011). The interview guide, based on previous research on psychosocial influence of strabismus, was designed by the doctoral researcher, reviewed by the research group and other doctoral researchers conducting qualitative interview study and edited accordingly (McGrath et al., 2019). The inclusion and exclusion criteria were defined clearly and purposive sampling using adults' responses on the AS-20 enhanced that the

interviewees had experiences on the psychosocial consequences of strabismus (Moser & Korstjens, 2017a). All these enhance the credibility of the sub-studies III and IV (Korstjens & Moser, 2018)

#### *Data collection*

Patients were interviewed individually once, and the interview situation was created to be calm and safe. The interviews were conducted either face-to face or online. Participants chose the time and place of the interview as recommended by McGrath et al. (2019). The doctoral researcher talked about herself, the reasons for conducting research, the process of the whole PhD study and the current qualitative study and data protection. Voluntary participation and informed consent to the study was confirmed prior commencing the interviews. Neither the interviewer nor the research group knew the participants beforehand. These strengthen the confirmability, dependability and credibility of the study (Elo et al., 2014; Korstjens & Moser, 2018).

The doctoral researcher was aware that the interview situation is a social interaction and as a researcher she influences the interview (Korstjens & Moser, 2017; McGrath et al., 2019). However, she prepared the interview situations beforehand, aimed to stay neutral and objective and critically self-reflected her actions afterwards (Cypress, 2017; Korstjens & Moser, 2018). Participants were encouraged to speak freely, however, some of them needed more support and guidance (Moser & Korstjens, 2017b). The participants could talk as long as they wanted to and at the end of the interview the researcher asked if there is anything else they would like to tell. Exploratory questions were used to understand experiences and confirm that the researcher had understood correctly what the participant had described. (Holloway & Galvin, 2017.) Authenticity, confirmability and dependability were enhanced by these actions (Elo et al., 2014; Korstjens & Moser, 2018).

The researcher's knowledge about strabismus and the influences on well-being helped the patients to trust her. At the same time, she was not a clinical expert of the condition and therefore she did not have the expectations for the adults' experiences. Data analysis was commenced after the second interview and continued simultaneously during the interview process. Data saturation was achieved after 10 interviews and two more interviews were conducted to confirm the saturation for the sub-study III. For the sub-study IV, the data saturated after 11 interviews. (Kyngäs, 2019b; Moser & Korstjens, 2017b.)

### *Data analysis*

Using inductive content analysis was decided as there was very fragmented understanding of psychosocial well-being due to strabismus or adults' expectations for psychosocial support (Kyngeäs, 2019b). The recorded interviews were transcribed verbatim after the interviews, the transcripts checked to see they were accurate to the original recordings and the data was read several times when the analysis was started (Kyngeäs, 2019a; McGrath et al., 2019; Moser & Korstjens, 2017b). Field notes, such as "emotional when talking about experiences in interactions" enhanced the analysis. Checking transcriptions and using field notes strengthened confirmability and credibility of the data analysis (Korstjens & Moser, 2018). The analysis was conducted manually by the doctoral researcher and analysis was reflected several times with the research team to accurately reflect the participants' experiences increasing reflexivity of the analysis (Elo et al., 2014).

The analyses were conducted separately one research question at a time to ensure credibility, dependability, confirmability, authenticity and reflexivity of the sub-studies III and IV (Cypress, 2017; Elo et al., 2014; Korstjens & Moser, 2018). The analysis is described from the units of analysis to open codes, subcategories, categories and main categories and an example of the analysis is provided. This helps readers or other researchers follow the analysis process and thus increases trustworthiness of sub-studies (Elo et al., 2014). Self-awareness of previous understanding of psychosocial consequences and researcher bias was integral in data analysis (Cypress, 2017). Otherwise, it would have been difficult to understand the meaning of some of the participants' experiences, such as avoidance of eye contact in general interactions but in the interview, it was okay to look at the interviewer into eyes as she knew about strabismus. At the same time the researcher self-reflected regularly her decisions to increase trustworthiness. Data analysis continued whilst reporting the results (Korstjens & Moser, 2018) and participants' ID codes enabled the return to the transcribed text to check the original meaning units.

### *Results*

Both men and women are represented in the participants and the age groups of the strabismic adults cover the age spectrum of adult patients in the unit. It is imperative to notice that onset of strabismus varies and that can impact the influences of strabismus and should be considered in the future qualitative studies.

Therefore, the onset of strabismus is included in the description of participants to ensure credibility (Elo et al., 2014; Korstjens & Moser, 2018).

The results are reported with participants' authentic quotations to increase trustworthiness (Elo et al., 2014). It is noteworthy that the original language of the interviews was Finnish, and great care was utilised for translation of the quotations. This included discussions with a native English speaker to make sure that even the slightest language tones were kept. It is possible that the translation has decreased the credibility of the study. The participants did not check the results of the sub-studies III and IV and it might decrease dependability of the sub-studies (Korstjens & Moser, 2018).

It is also worth considering the transferability of the results to other strabismic or ophthalmic patients. The results describe the experiences of 12 strabismic adults of psychosocial influences of strabismus and concur with clinical experience and limited previous research evidence. However, the transfer of the results to other strabismic patients should be done with care as strabismus is an umbrella term for many types of strabismus and not all strabismic adults have psychosocial hindrance of their condition or a need for psychosocial support. Therefore, it would be important to evaluate patient's HRQOL to understand their struggles to provide holistic care. Considering transferability to some of the other patient groups in ophthalmology, it is important to note that patients with cataract, glaucoma or diabetic retinopathy are generally older whereas strabismus is present in all age groups. Additionally, these patients might often have varied stages of visual impairments which may impact their well-being and need for psychosocial support which differs from strabismic adults. These influence transferability of this study results directly to other ophthalmic patients. However, the doctoral researcher has aimed to describe the research design, settings, participants, data and analysis clearly so the reader can assess if the results are transferable (Elo et al., 2014).

## 6.5 Implications for practice

The results of this study can be used to develop clinical strabismus care in ophthalmic departments. Although the setting of the study was a university hospital, strabismic patients are also cared for in central hospitals in Finland. Using the Finnish AS-20 to assess patients' HRQOL is recommended. The measure gives a quick insight into the struggles a patient has with strabismus and a professional can focus on those struggles rather than trying to find them out by interviewing.

Longitudinal use of the AS-20 on a patient during the care process enables assessing the effect of treatment and it is important the scores are available as outcome measures after surgery. In the financial situation of public healthcare sector, strabismic adults' care needs to be also measured by a change on their HRQOL.

Strabismus has impacts on one's general functioning and it can be assessed in the appointments. The influence on psychosocial well-being might be easily forgotten. Patient AS-20 responses can also be used as a tool to discuss difficult subjects, such as one's psychosocial well-being. Specialists working in strabismus services need to educate public and healthcare professionals on the psychosocial influence of strabismus as the participants described that strabismus is not well-known. This includes school nurses as they are key people among the children and adolescent well-being. The pathways to care should be assessed.

Psychosocial support needs to be provided for the strabismic adults at all levels of healthcare. This study provides recommendations for the support to strabismic adults patients. Strabismic adult patients and the multidisciplinary team need to be involved in development of support intervention.

## 6.6 Further research recommendations

Strabismic adults' HRQOL has been studied internationally from different contexts and it would be interesting to know how Finnish strabismic adults' and international study results meet. Longitudinal study of the effect of strabismus surgery on HRQOL is already in progress. Further studies could be conducted on influences of strabismus on whole HRQOL by qualitative method with diplopia and type of strabismus as a background variable. It would be interesting to see whether Finnish patients would describe similar influences than for example in the USA or China. Patients would benefit of development of psychosocial support as an intervention. It would be important to assess the developed intervention for feasibility and the effectiveness on HRQOL and implemented with research evidence into clinical practice. Additionally, the validation process of Finnish AS-20 should continue.

Children and young people must not be forgotten. The influence of strabismus might be different with children or adolescents. They also have an own HRQOL measures which could be translated, adapted and validated in Finnish language and culture (Hatt et al., 2019b; Hatt et al., 2010b). It would also be important to develop psychosocial care for strabismic children and adolescents. HRQOL generally is a



very interesting topic to study further. As ophthalmic nursing is not studied widely in international or national context, there are many opportunities for further research to develop the clinical services and patient care.

## 7 CONCLUSIONS

This study concludes the following on strabismic adult' health-related quality of life and expectations for psychosocial support:

1. The Finnish AS-20 is a feasible, clear and understandable measure with good reliability and psychometric properties for assessing strabismic adults' HRQOL both in clinical practice and research.
2. The refined AS-20 is the most satisfactory structure for research and needs further validation.
3. In all three Finnish AS-20 structures scores should be calculated by computing the mean of all completed items.
4. Finnish strabismic adults had both functional and psychosocial adverse impacts of strabismus.
5. Patients who did not experience diplopia had lower psychosocial HRQOL in self-perception and interaction than the patients who experienced diplopia.
6. Strabismic adult patients described varied psychosocial influences of strabismus both as challenges with social environments and struggles with mental well-being which impaired their HRQOL.
7. Strabismic adults expressed the need for psychosocial support which should consist of education of strabismus, genuine encounter with the healthcare professionals, accessible support and available peer support.
8. Healthcare professionals caring for strabismic adults should educate other healthcare professionals, particularly primary care and school health, and the public on strabismus and its' impacts.
9. Psychosocial support for strabismic adults needs to be co-developed with patients and offered to strabismic adults as needed.

## 8 REFERENCES

- Adams, G. G. W., McBain, H., MacKenzie, K., Hancox, J., Ezra, D. G., & Newman, S. P. (2016). Is strabismus the only problem? Psychological issues surrounding strabismus surgery. *Journal of AAPOS: The Official Publication of the American Association for Pediatric Ophthalmology and Strabismus*, 20(5), 383–386. <https://doi.org/10.1016/j.jaapos.2016.07.221>
- Akbari, M. R., Masoomian, B., Ameri, A., Keshtkar Jaafari, A., & Mirmohammadsadeghi, A. (2015). Development of a Persian Version of the Adult Strabismus Questionnaire and Evaluating the Effect of Strabismus Surgery on Health-Related Quality of Life. *Strabismus*, 23(2), 66–72. <https://doi.org/10.3109/09273972.2015.1025986>
- Alam, D., Khan, A. A., Bani, S. A., Sharma, R., & Amitava, A. K. (2014). Gain beyond cosmesis: Demonstration of psychosocial and functional gains following successful strabismus surgery using the Adult Strabismus questionnaire Adult Strabismus 20. *Indian Journal of Ophthalmology*, 62(7), 799–803. <https://doi.org/10.4103/0301-4738.138620>
- Alamri, R., Alyousef, M., Bamardouf, N., Alharbi, B., & Raffa, L. (2022). Validation of the health-related quality of life questionnaire for adult strabismus AS-20 in the Arabic language. *Saudi Journal for Health Sciences*, 11(3), 197. [https://doi.org/10.4103/sjhs.sjhs\\_113\\_22](https://doi.org/10.4103/sjhs.sjhs_113_22)
- Ali, N., Sørensen, M. S., Sørensen, T. L., & Mortzos, P. (2015). Evaluation and validity of the Danish version of the Adult Strabismus Questionnaire AS-20. *Clinical Ophthalmology*, 65. <https://doi.org/10.2147/OPHTH.S90844>
- ALLEA - All European Academies. (2023). *The European Code of Conduct for Research Integrity*. ALLEA - All European Academies. <https://doi.org/10.26356/ECOC>. Accessed: 11<sup>th</sup> May 2024.
- Al-Omari, R., Jammal, H. M., Khader, Y., Atoum, D., Al-Dolat, W., & Khatatbeh, M. (2022). Adults with Longstanding Strabismus: Psychosocial and Functional Impacts and Reasons behind Surgery Delay. *Journal of Ophthalmology*, 2022, 8682675. <https://doi.org/10.1155/2022/8682675>
- Alpak, G., Coskun, E., Erbagci, I., Bez, Y., Okumus, S., Oren, B., & Gurler, B. (2014). Effects of corrective surgery on social phobia, psychological distress, disease-related disability and quality of life in adult strabismus patients. *The British Journal of Ophthalmology*, 98(7), 876–879. <https://doi.org/10.1136/bjophthalmol-2014-304888>
- Anthoine, E., Moret, L., Regnault, A., Sébille, V., & Hardouin, J.-B. (2014). Sample size used to validate a scale: A review of publications on newly-developed patient reported outcomes measures. *Health and Quality of Life Outcomes*, 12(1), 2. <https://doi.org/10.1186/s12955-014-0176-2>

- Arblaster, G., Buckley, D., Barnes, S., & Davis, H. (2024a). Strabismus Surgery for Psychosocial Reasons—A Literature Review. *British and Irish Orthoptic Journal*, 20(1), 107–132. <https://doi.org/10.22599/bioj.352>
- Arblaster, G. E., Davis, H., Buckley, D., & Barnes, S. (2024b). Patient perspectives on their outcomes from strabismus surgery undertaken for psychosocial reasons. *Eye*, 1–6. <https://doi.org/10.1038/s41433-024-03189-9>
- Aroian, K. J., & Norris, A. E. (2005). Confirmatory factor analysis. In B. H. Munro (Ed.), *Statistical Methods for Health Care Research*. (5th ed.). Lippincott Williams & Wilkins.
- Assaye, A. K., Tegegn, M. T., Assefa, N. L., & Yibekal, B. T. (2020). Knowledge towards Strabismus and Associated Factors among Adults in Gondar Town, Northwest Ethiopia: Journal of Ophthalmology. *Journal of Ophthalmology*, 1–7. <https://doi.org/10.1155/2020/3639273>
- AVI. (2024). *Rights and status of patients*. <https://avi.fi/en/services/individuals/guidance-and-advice/patients-rights>. Accessed: 10<sup>th</sup> August 2024.
- Backman, K., & Hentinen, M. (2001). Factors associated with the self-care of home-dwelling elderly. *Scandinavian Journal of Caring Sciences*, 15(3), 195–202. <https://doi.org/10.1046/j.1471-6712.2001.00007.x>
- Bandhu, S., Raje, S., Kaur, B., Moudgil, T., & Bansal, Y. (2023). Comparison of psychosocial impact of strabismus on pediatric and adult patients in India. *Journal of Clinical Ophthalmology and Research*, 11(3), 146. [https://doi.org/10.4103/jcor.jcor\\_119\\_22](https://doi.org/10.4103/jcor.jcor_119_22)
- Battista Marcon, G., & Pittino, R. (2017). The Italian version of the Adult Strabismus-20 (AS-20) questionnaire: Translation validation and reliability. *New Frontiers in Ophthalmology*, 3(5). <https://doi.org/10.15761/NFO.1000179>
- Beauchamp, C. L., Beauchamp, G. R., Stager, D. R. S., Brown, M. M., Brown, G. C., & Felius, J. (2006). The cost utility of strabismus surgery in adults. *Journal of AAPOS: The Official Publication of the American Association for Pediatric Ophthalmology and Strabismus*, 10(5), 394–399. <https://doi.org/10.1016/j.jaapos.2006.06.004>
- Beauchamp, G. R., Black, B. C., Coats, D. K., Enzenauer, R. W., Hutchinson, A. K., Saunders, R. A., Simon, J. W., Stager, D. R. J., Stager, D. R. S., Wilson, M. E., Zobal-Ratner, J., & Felius, J. (2005). The management of strabismus in adults—III. The effects on disability. *Journal of AAPOS: The Official Publication of the American Association for Pediatric Ophthalmology and Strabismus*, 9(5), 455–459. <https://doi.org/10.1016/j.jaapos.2005.04.009>
- Beauchamp, G. R., Felius, J., Stager, D. R., & Beauchamp, C. L. (2005). The utility of strabismus in adults. *Transactions of the American Ophthalmological Society*, 103, 164–171; discussion 171-172.
- Bertelmann, T., Feltgen, N., Scheffler, M., Hufenbach, U., Wiedon, A., Wilhelm, H., & Ziemssen, F. (2016). Vision-related quality of life in patients receiving intravitreal ranibizumab injections in routine clinical practice: Baseline data from the German OCEAN study: Health & Quality of Life Outcomes. *Health & Quality of Life Outcomes*, 14, 1–11. <https://doi.org/10.1186/s12955-016-0536-1>

- Bez, Y., Coşkun, E., Erol, K., Cingu, A. K., Eren, Z., Topçuoğlu, V., & Özertürk, Y. (2009). Adult strabismus and social phobia: A case-controlled study. *Journal of American Association for Pediatric Ophthalmology and Strabismus*, 13(3), 249–252. <https://doi.org/10.1016/j.japos.2009.02.010>
- Bian, W., Li, M., Wang, Z., Wang, X., Liu, Y., & Wu, Y. (2015). Psychometric properties of the Chinese version of the Amblyopia and Strabismus Questionnaire (ASQE). *Health and Quality of Life Outcomes*, 13, 81. <https://doi.org/10.1186/s12955-015-0269-6>
- Borwick, G. (2011). A holistic approach to meeting the needs of patients with conditions that affect their appearance. *Primary Health Care (through 2013)*, 21(1), 33–39.
- Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a Qualitative Description Approach in Health Care Research. *Global Qualitative Nursing Research*, 4, 2333393617742282. <https://doi.org/10.1177/2333393617742282>
- Breen, L. J., O’connor, M., Calder, S., Tai, V., Cartwright, J., & Beilby, J. M. (2017). The health professionals’ perspectives of support needs of adult head and neck cancer survivors and their families: A Delphi study. *Supportive Care in Cancer*, 25(8), 2413–2420. <https://doi.org/10.1007/s00520-017-3647-2>
- Buchholz, S. W., & Dickins, K. A. (2023). *Literature review and synthesis: A guide for nurses and other healthcare professionals* (First Springer Publishing edition). Springer Publishing Company, LLC.
- Buffenn, A. N. (2021). The impact of strabismus on psychosocial health and quality of life: A systematic review. *Survey of Ophthalmology*, 66(6), 1051–1064. <https://doi.org/10.1016/j.survophthal.2021.03.005>
- Burggraaf, F., Elsman, E. B., van Nispen, R. M., Tjon-Fo-Sang, M. J., Spek, B., & Jellema, H. M. (2021). Psychometric properties of the Dutch version Adult Strabismus-20 Questionnaire (AS-20). *Ophthalmic & Physiological Optics: The Journal of the British College of Ophthalmic Opticians (Optometrists)*, 41(5), 1007–1020. <https://doi.org/10.1111/opo.12865>
- Cameron, J. I., & Gignac, M. A. M. (2008). “Timing It Right”: A conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient Education and Counseling*, 70(3), 305–314. <https://doi.org/10.1016/j.pec.2007.10.020>
- Carlton, J., & Kaltenthaler, E. (2011). Health-related quality of life measures (HRQoL) in patients with amblyopia and strabismus: A systematic review. *The British Journal of Ophthalmology*, 95(3), 325–330. <https://doi.org/10.1136/bjo.2009.178889>
- Chang, M., Wang, H., & Niu, T. (2021). Influence of psychological nursing on negative emotion and sleep quality of glaucoma trabeculectomy patients. *American Journal of Translational Research*, 13(7), 8415–8420.
- Chang, M. Y., Velez, F. G., Demer, J. L., Isenberg, S. J., Coleman, A. L., & Pineles, S. L. (2015). Quality of life in adults with strabismus. *American Journal of Ophthalmology*, 159(3), 539-544.e2. <https://doi.org/10.1016/j.ajo.2014.12.003>

- Chow, S. C., Lam, P. Y., & Choy, B. N. K. (2022). Patient-centred care in ophthalmology: Current practices, effectiveness and challenges. *Graefe's Archive for Clinical and Experimental Ophthalmology*, 260(10), 3149–3159. <https://doi.org/10.1007/s00417-022-05666-x>
- Coats, D. K., Paysse, E. A., Towler, A. J., & Dipboye, R. L. (2000). Impact of large angle horizontal strabismus on ability to obtain employment. *Ophthalmology*, 107(2), 402–405. [https://doi.org/10.1016/S0161-6420\(99\)00035-4](https://doi.org/10.1016/S0161-6420(99)00035-4)
- Comiskey, C., & Dempsey, O. (2013). Analysing data from small and large samples and non-normal and normal distributions. In E. A. Curtis & J. Drennan (Eds.), *Quantitative health research: Issues and methods* (Vol. 1). McGraw-Hill Education.
- Çoşkun, H., Taştan, S., Iyigün, E., Mutlu, F. M., Ceylan, O. M., & Altınsoy, H. İ. (2017). A study on the validity and reliability of the Amblyopia and Strabismus Questionnaire (A&SQ) in Turkish. *Turkish Journal of Medical Sciences*, 47(2), 483–489. <https://doi.org/10.3906/sag-1512-86>
- Cypress, B. S. (2017). Rigor or Reliability and Validity in Qualitative Research: Perspectives, Strategies, Reconceptualization, and Recommendations. *Dimensions of Critical Care Nursing*, 36(4), 253–263. <https://doi.org/10.1097/DCC.0000000000000253>
- Dickmann, A., Aliberti, S., Rebecchi, M. T., Aprile, I., Salerno, A., Petroni, S., Parrilla, R., Perrotta, V., Di Nardo, E., & Balestrazzi, E. (2013). Improved sensory status and quality-of-life measures in adult patients after strabismus surgery. *Journal of AAPOS: The Official Publication of the American Association for Pediatric Ophthalmology and Strabismus*, 17(1), 25–28. <https://doi.org/10.1016/j.jaapos.2012.09.017>
- Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction With Life Scale. *Journal of Personality Assessment*, 49(1), 71–75. [https://doi.org/10.1207/s15327752jpa4901\\_13](https://doi.org/10.1207/s15327752jpa4901_13)
- Duffy, M. E., Munro, B. H., & Jacobsen, B. S. (2005). Key principles of Statistical Inference. In B. H. Munro (Ed.), *Statistical methods for health care research* (5th ed.). Lippincott Williams & Wilkins.
- Durnian, J. M., Noonan, C. P., & Marsh, I. B. (2011). The psychosocial effects of adult strabismus: A review. *The British Journal of Ophthalmology*, 95(4), 450–453. <https://doi.org/10.1136/bjo.2010.188425>
- Durnian, J. M., Owen, M. E., Baddon, A. C., Noonan, C. P., & Marsh, I. B. (2010). The psychosocial effects of strabismus: Effect of patient demographics on the AS-20 score. *Journal of AAPOS: The Official Publication of the American Association for Pediatric Ophthalmology and Strabismus*, 14(6), 469–471. <https://doi.org/10.1016/j.jaapos.2010.08.013>
- Durnian, J. M., Owen, M. E., & Marsh, I. B. (2009). The psychosocial aspects of strabismus: Correlation between the AS-20 and DAS59 quality-of-life questionnaires. *Journal of AAPOS: The Official Publication of the American Association for Pediatric Ophthalmology and Strabismus*, 13(5), 477–480. <https://doi.org/10.1016/j.jaapos.2009.06.006>
- Ehlers, M., Mauschitz, M. M., & Wabbels, B. (2023). Implementing strabismus-specific psychosocial questionnaires in everyday clinical practice: Mental health and quality of

- life in the context of strabismus surgery. *BMJ Open Ophthalmology*, 8(1).  
<https://doi.org/10.1136/bmjophth-2023-001334>
- El Meshad, N., Soliman, H., Hunt, S., Amarakoon, S., Ahmad, A., Ford, R., Harrad, R., & Choleva, V. (2024). Psychological and functional outcomes of horizontal squint surgery in adults with no preoperative diplopia using Quality-of-Life AS-20 questionnaire. *British Journal of Ophthalmology*, bjo-2023-324719.  
<https://doi.org/10.1136/bjo-2023-324719>
- Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). Qualitative Content Analysis: A Focus on Trustworthiness. *Sage Open*, 4(1), 2158244014522633. <https://doi.org/10.1177/2158244014522633>
- Estcourt, S., Vaidya, B., Quinn, A., & Shepherd, M. (2008). The impact of thyroid eye disease upon patients' wellbeing: A qualitative analysis. *Clinical Endocrinology*, 68(4), 635–639.  
<https://doi.org/10.1111/j.1365-2265.2007.03087.x>
- Estes, K. J., Parrish, R. K., Sinacore, J., Mumby, P. B., & McDonnell, J. F. (2020). Effects of corrective strabismus surgery on social anxiety and self-consciousness in adults. *Journal of American Association for Pediatric Ophthalmology and Strabismus*, 24(5), 280.e1-280.e4. <https://doi.org/10.1016/j.jaapos.2020.05.017>
- Fang, S. Y., Gandhi, N., Satterfield, D., & O'Hara, M. (2018). Strabismus surgery for Medicare-aged patients: More than a decade of insights. *Journal of AAPOS : The Official Publication of the American Association for Pediatric Ophthalmology and Strabismus*, 22(3), 170-173.e1. <https://doi.org/10.1016/j.jaapos.2017.12.017>
- Felius, J., Beauchamp, G. R., Stager, D. R. S., Van De Graaf, E. S., & Simonsz, H. J. (2007). The Amblyopia and Strabismus Questionnaire: English translation, validation, and subscales. *American Journal of Ophthalmology*, 143(2), 305–310.  
<https://doi.org/10.1016/j.ajo.2006.09.046>
- Ferrans, C. E., Zerwic, J. J., Wilbur, J. E., & Larson, J. L. (2005). Conceptual Model of Health-Related Quality of Life. *Journal of Nursing Scholarship*, 37(4), 336–342.  
<https://doi.org/10.1111/j.1547-5069.2005.00058.x>
- Fieß, A., Elflein, H. M., Urschitz, M. S., Pesudovs, K., Münzel, T., Wild, P. S., Michal, M., Lackner, K. J., Pfeiffer, N., Nickels, S., & Schuster, A. K. (2020). Prevalence of Strabismus and Its Impact on Vision-Related Quality of Life: Results from the German Population-Based Gutenberg Health Study. *Ophthalmology*, 127(8), 1113–1122. <https://doi.org/10.1016/j.ophtha.2020.02.026>
- FINLEX, 785/1992. (1992). *Act on the status and rights of patients 785/1992, unofficial translation*. Ministry of Social Affairs and Health, Finland. [https://www.finlex.fi/en/laki/kaannokset/1992/en19920785\\_20120690.pdf](https://www.finlex.fi/en/laki/kaannokset/1992/en19920785_20120690.pdf). Accessed: 10<sup>th</sup> August 2024.
- FINLEX, 1326/2010. (2010). *Health Care Act 1326/2010, unofficial translation*. Ministry of Social Affairs and Health, Finland. Ministry of Social Affairs and Health, Finland. [https://finlex.fi/en/laki/kaannokset/2010/en20101326\\_20131293.pdf](https://finlex.fi/en/laki/kaannokset/2010/en20101326_20131293.pdf). Accessed: 10<sup>th</sup> August 2024.

- Flodin, S., Rydberg, A., Pansell, T., & Grönlund, M. A. (2021). Measuring health-related quality of life in individuals with cyclodeviation using the Adult Strabismus 20 (AS-20) questionnaire. *Journal of AAPOS : The Official Publication of the American Association for Pediatric Ophthalmology and Strabismus*, 25(1), 20.e1-20.e6. <https://doi.org/10.1016/j.jaapos.2020.08.011>
- Fujūke, K., Mizuno, Y., Hiratsuka, Y., & Yamada, M. (2011). Quality of life and cost-utility assessment after strabismus surgery in adults. *Japanese Journal of Ophthalmology*, 55(3), 268–276. <https://doi.org/10.1007/s10384-011-0022-6>
- Gallienne, R. L., Moore, S. M., & Brennan, P. F. (1993). ALZHEIMER'S CAREGIVERS: Psychosocial Support via Computer Networks. *Journal of Gerontological Nursing*, 19(12), 15–22. <https://doi.org/10.3928/0098-9134-19931201-05>
- Glasman, P., Cheeseman, R., Wong, V., Young, J., & Durnian, J. M. (2013). Improvement in patients' quality-of-life following strabismus surgery: Evaluation of postoperative outcomes using the Adult Strabismus 20 (AS-20) score. *Eye*, 27(11), 1249–1253. <https://doi.org/10.1038/eye.2013.174>
- Goff, M. J., Suhr, A. W., Ward, J. A., Croley, J. K., & O'Hara, M. A. (2006). Effect of Adult Strabismus on Ratings of Official U.S. Army Photographs. *Journal of American Association for Pediatric Ophthalmology and Strabismus*, 10(5), 400–403. <https://doi.org/10.1016/j.jaapos.2006.04.011>
- Gothwal, V. K., Bharani, S., Kekunnaya, R., Chhablani, P., Sachdeva, V., Pehera, N. K., Narasaiah, A., & Gunturu, R. (2015). Measuring Health-Related Quality of Life in Strabismus: A Modification of the Adult Strabismus-20 (AS-20) Questionnaire Using Rasch Analysis. *PLoS One*, 10(5), e0127064. <https://doi.org/10.1371/journal.pone.0127064>
- Gray, T., Fenerty C, Harper R, Spencer AF, Campbell M, Henson DB, Waterman H, Gray, T. A., Fenerty, C., Harper, R., Spencer, A. F., Campbell, M., Henson, D. B., & Waterman, H. (2012). Individualised patient care as an adjunct to standard care for promoting adherence to ocular hypotensive therapy: An exploratory randomised controlled trial: *Eye*. *Eye*, 26(3), 407–417. <https://doi.org/10.1038/eye.2011.269>
- Gunton, K. B. (2014). Impact of strabismus surgery on health-related quality of life in adults. *Current Opinion in Ophthalmology*, 25(5), 406–410. <https://doi.org/10.1097/ICU.0000000000000087>
- Guyatt, G. H., Ferrans, C. E., Halyard, M. Y., Revicki, D. A., Symonds, T. L., Varricchio, C. G., Kotzeva, A., Valderas, J. M., & Alonso, J. L. (2007). Exploration of the Value of Health-Related Quality-of-Life Information From Clinical Research and Into Clinical Practice. *Mayo Clinic Proceedings*, 82(10), 1229–1239. <https://doi.org/10.4065/82.10.1229>
- Hair, J. F. (Ed.). (1998). *Multivariate data analysis* (5. ed., internat. ed). Prentice-Hall.
- Hancox, J., Sharma, S., MacKenzie, K., & Adams, G. (2012). The effect on quality of life of long-term botulinum toxin A injections to maintain ocular alignment in adult patients with strabismus. *The British Journal of Ophthalmology*, 96(6), 838–840. <https://doi.org/10.1136/bjophthalmol-2011-301332>



- Hark, L. A., Madhava, M., Radakrishnan, A., Anderson-Quñones, C., Robinson, D., Adeghate, J., Silva, S., Zhan, T., Adepoju, T., Dave, Y., & Fudemberg, S. J. (2019). Impact of a Social Worker in a Glaucoma Eye Care Service: A Prospective Study: Health & Social Work. *Health & Social Work, 44*(1), 48–56. <https://doi.org/10.1093/hsw/hly038>
- Hashemi, H., Pakzad, R., Heydarian, S., Yekta, A., Aghamirsalim, M., Shokrollahzadeh, F., Khoshhal, F., Pakbin, M., Ramin, S., & Khabazkhoob, M. (2019). Global and regional prevalence of strabismus: A comprehensive systematic review and meta-analysis. *Strabismus, 27*(2), 54–65. <https://doi.org/10.1080/09273972.2019.1604773>
- Hassan, M. B., Hodge, D. O., & Mohney, B. G. (2015). Prevalence of Mental Health Illness among Patients with Adult-Onset Strabismus. *Strabismus, 23*(3), 105–110. <https://doi.org/10.3109/09273972.2015.1070881>
- Hatt, S. R., Leske, D. A., Bradley, E. A., Cole, S. R., & Holmes, J. M. (2009a). Development of a quality-of-life questionnaire for adults with strabismus. *Ophthalmology, 116*(1), 139–144.e5. <https://doi.org/10.1016/j.ophtha.2008.08.043>
- Hatt, S. R., Leske, D. A., Castañeda, Y. S., Wernimont, S. M., Liebermann, L., Cheng-Patel, C. S., Birch, E. E., & Holmes, J. M. (2019b). Development of Pediatric Eye Questionnaires for Children With Eye Conditions. *American Journal of Ophthalmology, 200*, 201–217. <https://doi.org/10.1016/j.ajo.2019.01.001>
- Hatt, S. R., Leske, D. A., & Holmes, J. M. (2010a). Responsiveness of health-related quality-of-life questionnaires in adults undergoing Strabismus surgery. *Ophthalmology, 117*(12), 2322–2328.e1. <https://doi.org/10.1016/j.ophtha.2010.03.042>
- Hatt, S. R., Leske, D. A., & Holmes, J. M. (2019a). Patient-derived questionnaire items for patient-reported outcome measures in adults with strabismus. *Journal of AAPOS : The Official Publication of the American Association for Pediatric Ophthalmology and Strabismus, 23*(2), 100–101.e3. <https://doi.org/10.1016/j.jaapos.2018.11.004>
- Hatt, S. R., Leske, D. A., Kirgis, P. A., Bradley, E. A., & Holmes, J. M. (2007). The effects of strabismus on quality of life in adults. *American Journal of Ophthalmology, 144*(5), 643–647. <https://doi.org/10.1016/j.ajo.2007.06.032>
- Hatt, S. R., Leske, D. A., Liebermann, L., & Holmes, J. M. (2012b). Comparing outcome criteria performance in adult strabismus surgery. *Ophthalmology, 119*(9), 1930–1936. <https://doi.org/10.1016/j.ophtha.2012.02.035>
- Hatt, S. R., Leske, D. A., Liebermann, L., & Holmes, J. M. (2014b). Successful treatment of diplopia with prism improves health-related quality of life. *American Journal of Ophthalmology, 157*(6), 1209–1213. <https://doi.org/10.1016/j.ajo.2014.02.033>
- Hatt, S. R., Leske, D. A., Liebermann, L., & Holmes, J. M. (2016). Incorporating Health-related Quality of Life Into the Assessment of Outcome Following Strabismus Surgery. *American Journal of Ophthalmology, 164*, 1–5. <https://doi.org/10.1016/j.ajo.2015.12.029>
- Hatt, S. R., Leske, D. A., Liebermann, L., Philbrick, K. L., & Holmes, J. M. (2014a). Depressive symptoms associated with poor health-related quality of life in adults with

- strabismus. *Ophthalmology*, 121(10), 2070–2071. <https://doi.org/10.1016/j.ophtha.2014.04.031>
- Hatt, S. R., Leske, D. A., Philbrick, K. L., & Holmes, J. M. (2018). Factors Associated With Failure of Adult Strabismus-20 Questionnaire Scores to Improve Following Strabismus Surgery. *JAMA Ophthalmology*, 136(1), 46–52. <https://doi.org/10.1001/jamaophthalmol.2017.5088>
- Hatt, S. R., Leske, D. A., Yamada, T., Bradley, E. A., Cole, S. R., & Holmes, J. M. (2010b). Development and initial validation of quality of life questionnaires for intermittent exotropia. *Ophthalmology*, 117(1), 163. <https://doi.org/10.1016/j.ophtha.2009.06.038>
- Hatt, S. R., Leske, D. A., Bradley, E. A., Cole, S. R., & Holmes, J. M. (2009b). Comparison of quality-of-life instruments in adults with strabismus. *American Journal of Ophthalmology*, 148(4), 558–562. <https://doi.org/10.1016/j.ajo.2009.05.009>
- Hatt, S. R., Leske, D. A., Liebermann, L., & Holmes, J. M. (2012a). Changes in health-related quality of life 1 year following strabismus surgery. *American Journal of Ophthalmology*, 153(4), 614–619. <https://doi.org/10.1016/j.ajo.2011.10.001>
- Hays, R. D., & Morales, L. S. (2001). The RAND-36 measure of health-related quality of life. *Annals of Medicine*, 33(5), 350–357. <https://doi.org/10.3109/07853890109002089>
- Hernandez-Moreno, L., Senra, H., Moreno, N., & Macedo, A. F. (2021). Is perceived social support more important than visual acuity for clinical depression and anxiety in patients with age-related macular degeneration and diabetic retinopathy? *Clinical Rehabilitation*, 35(9), 1341–1347. <https://doi.org/10.1177/0269215521997991>
- Holloway, I., & Galvin, K. (2017). *Qualitative research in nursing and healthcare* (4th edition). John Wiley & Sons Inc.
- Holmes, J. M., Leske, D. A., & Kupersmith, M. J. (2005). New Methods for Quantifying Diplopia. *Ophthalmology*, 112(11), 2035–2039. <https://doi.org/10.1016/j.ophtha.2005.06.013>
- Horowitz, A., Reinhardt JP, Boerner K, & Travis LA. (2003). The influence of health, social support quality and rehabilitation on depression among disabled elders: Aging & Mental Health. *Aging & Mental Health*, 7(5), 342–350. <https://doi.org/10.1080/1360786031000150739>
- Hu, L., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling: A Multidisciplinary Journal*, 6(1), 1–55. <https://doi.org/10.1080/10705519909540118>
- Hua, Y., Lu, H., Dai, J., Zhou, Y., Zhou, W., Wang, A., Chen, Y., & Liang, Y. (2023). Self-management challenges and support needs among patients with primary glaucoma: A qualitative study. *BMC Nursing*, 22(1), 426. <https://doi.org/10.1186/s12912-023-01527-y>
- Huang, T. L., & Pineles, S. L. (2023). Strabismus and Pediatric Psychiatric Illness: A Literature Review. *Children*, 10(4), 607. <https://doi.org/10.3390/children10040607>

- INEE. (2018). *INEE Guidance Note on Psychosocial Support* [Guide]. Inter-agency Network for Education in Emergencies. <https://inee.org/resources/inee-guidance-notes-psychosocial-support>. Accessed: 18<sup>th</sup> July 2024.
- Jackson, S., Harrad, R. A., Morris, M., & Rumsey, N. (2006). The psychosocial benefits of corrective surgery for adults with strabismus. *The British Journal of Ophthalmology*, *90*(7), 883–888. <https://doi.org/10.1136/bjo.2005.089516>
- Jackson, S., Morris, M., & Gleeson, K. (2013). The long-term psychosocial impact of corrective surgery for adults with strabismus. *The British Journal of Ophthalmology*, *97*(4), 419–422. <https://doi.org/10.1136/bjophthalmol-2012-302983>
- Ji, N., Xu, M., Yu, H., Xu, J., & Yu, X. (2020). Factors influencing the self-reported sense of deviation in adults with successful surgical outcomes for strabismus. *BMC Ophthalmology*, *20*(1), 1–6. <https://doi.org/10.1186/s12886-019-1299-3>
- Kaplan, R. M., & Hays, R. D. (2022). Health-Related Quality of Life Measurement in Public Health. *Annual Review of Public Health*, *43*(1), 355–373. <https://doi.org/10.1146/annurev-publhealth-052120-012811>
- Kempen, G. I. J. M., Ballemans, J., Ranchor, A. V., Van Rens, G. H. M. B., & Zijlstra, G. A. R. (2012). The impact of low vision on activities of daily living, symptoms of depression, feelings of anxiety and social support in community-living older adults seeking vision rehabilitation services. *Quality of Life Research*, *21*(8), 1405–1411. <https://doi.org/10.1007/s11136-011-0061-y>
- Khurana, R., Agrawal, S., Singh, V., & Agrawal, M. (2021). Strabismus surgery in poor binocular potential: Change in quality of life. *Journal of Clinical Ophthalmology and Research*, *9*(3), 112. [https://doi.org/10.4103/jcor.jcor\\_88\\_19](https://doi.org/10.4103/jcor.jcor_88_19)
- Killeen, O. J., Niziol, L. M., Cho, J., Heisler, M., Resnicow, K., Darnley-Fisch, D., Musch, D., Lee, P., & Newman-Casey, P. A. (2023). Glaucoma Medication Adherence One Year After the Support, Educate, Empower (SEE) Personalized Glaucoma Coaching Program. *Ophthalmology. Glaucoma*, *6*(1), 23–28. <https://doi.org/10.1016/j.ogla.2022.08.001>
- Kim, Y., Kim, C., Kim, S., Han, Y., Chung, I., Seo, S., Park, J., & Yoo, J. (2016). Difference of Self-identity Levels between Strabismus Patients and Normal Controls. *Korean Journal of Ophthalmology*, *30*(6), 410. <https://doi.org/10.3341/kjo.2016.30.6.410>
- Kishimoto, F., & Ohtsuki, H. (2012). Comparison of VF-14 scores among different ophthalmic surgical interventions. *Acta Medica Okayama*, *66*(2), 101–110. <https://doi.org/10.18926/AMO/48260>
- Kleinschmidt, J. J. (1999). Older Adults' Perspectives on Their Successful Adjustment to Vision Loss. *Journal of Visual Impairment & Blindness*, *93*(2), 69–81. <https://doi.org/10.1177/0145482X9909300202>
- Koc, F., Erten, Y., & Yurdakul, N. S. (2013). Does restoration of binocular vision make any difference in the quality of life in adult strabismus. *The British Journal of Ophthalmology*, *97*(11), 1425–1430. <https://doi.org/10.1136/bjophthalmol-2013-303704>

- Korstjens, I., & Moser, A. (2017). Series: Practical guidance to qualitative research. Part 2: Context, research questions and designs. *The European Journal of General Practice*, 23(1). <https://www.proquest.com/docview/2195232997/abstract/9EDAFAAFCC5745F4PQ/1>
- Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *The European Journal of General Practice*, 24(1), 120–124. <https://doi.org/10.1080/13814788.2017.1375092>
- Kothari, M., & Joshi, V. (2014). The perceived personality traits of adults with digitally induced large angle strabismus and the impact of its correction. *Indian Journal of Ophthalmology*, 62(7), 773. <https://doi.org/10.4103/0301-4738.138617>
- Kraus, C., & Kuwera, E. (2023). What Is Strabismus? *JAMA*, 329(10), 856. <https://doi.org/10.1001/jama.2023.0052>
- Kumar, P., Campanile, J., Swenor, B. K., & Varadaraj, V. (2022). Stigma among older adults with age-related vision impairments. *Journal of Visual Impairment & Blindness*, 116(5), 689–698. <https://doi.org/10.1177/0145482X221132844>
- Kumaran, S. E., Khadka, J., Baker, R., & Pesudovs, K. (2018). Patient-reported outcome measures in amblyopia and strabismus: A systematic review. *Clinical & Experimental Optometry*, 101(4), 460–484. <https://doi.org/10.1111/cxo.12553>
- Kumaran, S. E., Khadka, J., Baker, R., & Pesudovs, K. (2019). Functional limitations recognised by adults with amblyopia and strabismus in daily life: A qualitative exploration. *Ophthalmic and Physiological Optics*, 39(3), 131–140. <https://doi.org/10.1111/opo.12610>
- Kyngäs, H. (2019a). Inductive content analysis. In H. Kyngäs, K. Mikkonen, & M. Kääriäinen (Eds.), *The application of content analysis in nursing science research* (Vol. 1, pp. 13–19). Springer International Publishing AG.
- Kyngäs, H. (2019b). Qualitative research and content analysis. In H. Kyngäs, K. Mikkonen, & M. Kääriäinen (Eds.), *The application of content analysis in nursing science research* (Vol. 1, pp. 3–11). Springer International Publishing AG.
- Laughton, S. C., Hagen, M. M., Wei Yang, & von Bartheld, C. S. (2023). Gender differences in horizontal strabismus: Systematic review and meta-analysis shows no difference in prevalence, but gender bias towards females in the clinic. *Journal of Global Health*, 13, 1–18. <https://doi.org/10.7189/jogh.13.04085>
- Lavallee, D. C., Chenok, K. E., Love, R. M., Petersen, C., Holve, E., Segal, C. D., & Franklin, P. D. (2016). Incorporating Patient-Reported Outcomes Into Health Care To Engage Patients And Enhance Care. *Health Affairs*, 35(4), 575–582. <https://doi.org/10.1377/hlthaff.2015.1362>
- Leske, D. A., Hatt, S. R., Liebermann, L., & Holmes, J. M. (2012). Evaluation of the Adult Strabismus-20 (AS-20) questionnaire using Rasch analysis. *Investigative Ophthalmology & Visual Science*, 53(6), 2630–2639. <https://doi.org/10.1167/iovs.11-8308>

- Leske, D. A., Hatt, S. R., & Holmes, J. M. (2010). Test-retest reliability of health-related quality-of-life questionnaires in adults with strabismus. *American Journal of Ophthalmology*, *149*(4), 672–676. <https://doi.org/10.1016/j.ajo.2009.11.004>
- Liebermann, L., Hatt, S. R., Leske, D. A., & Holmes, J. M. (2014). Improvement in specific function-related quality-of-life concerns after strabismus surgery in nondiplopic adults. *Journal of AAPOS: The Official Publication of the American Association for Pediatric Ophthalmology and Strabismus*, *18*(2), 105–109. <https://doi.org/10.1016/j.jaapos.2013.11.018>
- Lin, X.-J., Lin, I.-M., & Fan, S.-Y. (2013). Methodological issues in measuring health-related quality of life. *Tzu Chi Medical Journal*, *25*(1), 8–12. <https://doi.org/10.1016/j.tcmj.2012.09.002>
- Lindahl Norberg, A., & Strand, J. (2022). “We have to be the link between everyone”: A discursive psychology approach to defining registered nurses’ professional identity. *Nursing Open*, *9*(1), 222–232. <https://doi.org/10.1002/nop2.1056>
- MacKenzie, K., Hancox, J., McBain, H., Ezra, D. G., Adams, G., & Newman, S. (2016). Psychosocial interventions for improving quality of life outcomes in adults undergoing strabismus surgery. *The Cochrane Database of Systematic Reviews*, *2016*(5), CD010092. <https://doi.org/10.1002/14651858.CD010092.pub4>
- Mangione, C. M., Lee, P. P., Gutierrez, P. R., Spritzer, K., Berry, S., Hays, R. D., & National Eye Institute Visual Function Questionnaire Field Test Investigators. (2001). Development of the 25-item National Eye Institute Visual Function Questionnaire. *Archives of Ophthalmology (Chicago, Ill.: 1960)*, *119*(7), 1050–1058. <https://doi.org/10.1001/archophth.119.7.1050>
- Marcon, G. B., & Pittino, R. (2014). The Italian version of the Amblyopia and Strabismus Questionnaire: Translation, validation, and reliability. *Strabismus*, *22*(3), 100–110. <https://doi.org/10.3109/09273972.2014.932396>
- Margotto, F. S., Minguini, N., Batalha, C. P., De Melo, M. N., Alves, M., & De Carvalho, K. M. (2023). Translation and validation of a questionnaire on the impact of strabismus on the quality of life of patients. *Revista Brasileira de Oftalmologia*, *82*, e0007. <https://doi.org/10.37039/1982.8551.20230007>
- Marsh, I. B. (2015). We need to pay heed to the psychosocial aspects of strabismus. *Eye*, *29*(2), 238–240. <https://doi.org/10.1038/eye.2014.283>
- Mason, A., Joronen, K., Lindberg, L., Koivisto, A.-M., Fagerholm, N., & Rantanen, A. (2023). Health-Related Quality of Life in Adult Patients with Strabismus—Translation and Psychometric Testing of the Adult Strabismus Questionnaire (AS-20) into Finnish. *International Journal of Environmental Research and Public Health*, *20*(4), 2830. <https://doi.org/10.3390/ijerph20042830>
- McBain, H. B., Au, C. K., Hancox, J., MacKenzie, K. A., Ezra, D. G., Adams, G. G. W., & Newman, S. P. (2014b). The impact of strabismus on quality of life in adults with and without diplopia: A systematic review. *Survey of Ophthalmology*, *59*(2), 185–191. <https://doi.org/10.1016/j.survophthal.2013.04.001>

- McBain, H. B., MacKenzie, K. A., Au, C., Hancox, J., Ezra, D. G., Adams, G. G. W., & Newman, S. P. (2014a). Factors associated with quality of life and mood in adults with strabismus. *The British Journal of Ophthalmology*, *98*(4), 550–555. <https://doi.org/10.1136/bjophthalmol-2013-304220>
- McBain, H. B., MacKenzie, K. A., Hancox, J., Ezra, D. G., Adams, G. G. W., & Newman, S. P. (2016a). Does strabismus surgery improve quality and mood, and what factors influence this? *Eye (London, England)*, *30*(5), 656–667. <https://doi.org/10.1038/eye.2016.70>
- McBain, H., MacKenzie, K., Hancox, J., Ezra, D. G., Adams, G. G. W., & Newman, S. P. (2016b). What do patients with strabismus expect post surgery? The development and validation of a questionnaire. *The British Journal of Ophthalmology*, *100*(3), 415–419. <https://doi.org/10.1136/bjophthalmol-2015-307027>
- McGrath, C., Palmgren, P. J., & Liljedahl, M. (2019). Twelve tips for conducting qualitative research interviews: Medical Teacher. *Medical Teacher*, *41*(9), 1002–1006. <https://doi.org/10.1080/0142159X.2018.1497149>
- McGrath, C., Sidhu, K., & Mahl, H. (2017). Interventions that Facilitate the Occupational Engagement of Older Adults with Age-Related Vision Loss: Findings from a Scoping Review: Physical & Occupational Therapy in Geriatrics. *Physical & Occupational Therapy in Geriatrics*, *35*(1), 3–19. <https://doi.org/10.1080/02703181.2016.1267292>
- McKenzie, J. A., Capo, J. A., Nusz, K. J., Diehl, N. N., & Mohny, B. G. (2009). Prevalence and Sex Differences of Psychiatric Disorders in Young Adults Who Had Intermittent Exotropia as Children. *Archives of Ophthalmology*, *127*(6), 743. <https://doi.org/10.1001/archophthalmol.2009.68>
- Menon, V., Saha, J., Tandon, R., Mehta, M., & Khokhar, S. (2002). Study of the psychosocial aspects of strabismus. *Journal of Pediatric Ophthalmology and Strabismus*, *39*(4), 203–208. <https://doi.org/10.3928/0191-3913-20020701-07>
- Merrill, K., Satterfield, D., & O'Hara, M. (2010). Strabismus surgery on the elderly and the effects on disability. *Journal of AAPOS : The Official Publication of the American Association for Pediatric Ophthalmology and Strabismus*, *14*(2), 196–198. <https://doi.org/10.1016/j.jaapos.2009.12.282>
- Mohny, B. G., McKenzie, J. A., Capo, J. A., Nusz, K. J., Mrazek, D., & Diehl, N. N. (2008). Mental Illness in Young Adults Who Had Strabismus as Children. *Pediatrics*, *122*(5), 1033–1038. <https://doi.org/10.1542/peds.2007-3484>
- Mojon-Azzi, S. M., & Mojon, D. S. (2007). Opinion of Headhunters about the Ability of Strabismic Subjects to Obtain Employment. *Ophthalmologica*, *221*(6), 430–433. <https://doi.org/10.1159/000107506>
- Mojon-Azzi, S. M., & Mojon, D. S. (2009). Strabismus and employment: The opinion of headhunters. *Acta Ophthalmologica*, *87*(7), 784–788. <https://doi.org/10.1111/j.1755-3768.2008.01352.x>
- Mojon-Azzi, S. M., Potnik, W., & Mojon, D. S. (2008). Opinions of dating agents about strabismic subjects' ability to find a partner. *British Journal of Ophthalmology*, *92*(6), 765–769. <https://doi.org/10.1136/bjo.2007.128884>

- Moser, A., & Korstjens, I. (2017a). Series: Practical guidance to qualitative research. Part 1: Introduction. *European Journal of General Practice*, 23(1), 271–273. <https://doi.org/10.1080/13814788.2017.1375093>
- Moser, A., & Korstjens, I. (2017b). Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. *The European Journal of General Practice*, 24(1), 9–18. <https://doi.org/10.1080/13814788.2017.1375091>
- Munro, B. H. (2005a). Correlation. In B. H. Munro (Ed.), *Statistical Methods for Health Care Research* (5th ed., pp. 239–258). Lippincott Williams & Wilkins.
- Munro, B. H. (2005b). *Statistical methods for health care research* (5th ed). Lippincott Williams & Wilkins.
- Naufal, F., Gajwani, P., Medina, R., Dutson, M., Mariotti, S. P., & West, S. K. (2021). Knowledge of patient emotional health status: Impact on clinical care in glaucoma and retinal services. *BMJ Open Ophthalmology*, 6(1), e000640. <https://doi.org/10.1136/bmjophth-2020-000640>
- NCI. (2024). *NCI Dictionary of Cancer Terms*. National Cancer Institute Dictionary of Cancer Terms. <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/psychosocial-support>. Accessed: 18<sup>th</sup> July 2024.
- Nelson, B. A., Gunton, K. B., Lasker, J. N., Nelson, L. B., & Drohan, L. A. (2008). The psychosocial aspects of strabismus in teenagers and adults and the impact of surgical correction. *Journal of American Association for Pediatric Ophthalmology and Strabismus*, 12(1), 72-76.e1. <https://doi.org/10.1016/j.jaapos.2007.08.006>
- Newell, R., & Clarke, M. (2000). Evaluation of a self-help leaflet in treatment of social difficulties following facial disfigurement. *International Journal of Nursing Studies*, 37(5), 381–388. <https://doi.org/10.1016/S0020-7489%2800%2900017-1>
- NLM. (2024). *Psychosocial Support Systems MeSH Descriptor Data 2024*. National Library of Medicine. <https://meshb.nlm.nih.gov/record/ui?ui=D000072858>. Accessed: 18<sup>th</sup> July 2024.
- Olitsky, S. E., Sudesh, S., Graziano, A., Hamblen, J., Brooks, S. E., & Shaha, S. H. (1999). The negative psychosocial impact of strabismus in adults. *Journal of American Association for Pediatric Ophthalmology and Strabismus*, 3(4), 209–211. [https://doi.org/10.1016/S1091-8531\(99\)70004-2](https://doi.org/10.1016/S1091-8531(99)70004-2)
- Olson, J. H., Louwagie, C. R., Diehl, N. N., & Mohny, B. G. (2012). Congenital Esotropia and the Risk of Mental Illness by Early Adulthood. *Ophthalmology*, 119(1), 145–149. <https://doi.org/10.1016/j.ophtha.2011.06.035>
- Ortiz Montero, T., Lugo Boton, I. K., Montenegro, M. B., Mejía, J. C., Baquero, L., & Mejia-Vergara, A. J. (2023). Translation and transcultural adaptation of the AS-20 scale to measure quality of life in adults with strabismus in Colombia, a pilot study. *Archivos de La Sociedad Espanola de Oftalmologia*, 98(3), 142–149. <https://doi.org/10.1016/j.oftale.2022.11.005>

- Paduca, A., Arnaut, O., Lundmark, P. O., & Bruenech, J. R. (2021). Causes of concomitant strabismus surgery delay in teenagers and adults. *Strabismus*, 29(3), 151–157. <https://doi.org/10.1080/09273972.2021.1948070>
- PCORI. (2024). *Evidence Synthesis Reports and Interactive Visualizations*. Patient-Centered Outcomes Research Institute. <https://www.pcori.org/impact/evidence-synthesis-reports-and-interactive-visualizations>. Accessed: 10<sup>th</sup> August 2024.
- Persson, U., & Carlson, E. (2019). Conceptions of professional work in contemporary health care—Perspectives from registered nurses in somatic care: A phenomenographic study. *Journal of Clinical Nursing*, 28(1–2), 201–208. <https://doi.org/10.1111/jocn.14628>
- Pierce, E. (2013). Designing and conducting quantitative research studies. In E. Curtis & J. Drennan (Eds.), *Quantitative health research: Issues and methods* (1st ed., p. English). McGraw-Hill Education.
- Power, B., Murphy, M., & Stokes, J. (2018). The Impact of Strabismus Surgery on Irish Adults. *British and Irish Orthoptic Journal*, 14(1), 6–10. <https://doi.org/10.22599/bioj.107>
- Pybis, J., Thurston, M., Dennison, C. M., Broom, M., & Miller, A. (2016). The nature of emotional support and counselling provision for people with sight loss in the United Kingdom. *British Journal of Visual Impairment*, 34(2), 167–176. <https://doi.org/10.1177/0264619616633884>
- Qu, S. Q., & Dumay, J. (2011). The qualitative research interview. *Qualitative Research in Accounting and Management*, 8(3), 238–264. <https://doi.org/10.1108/11766091111162070>
- Ribeiro, G. de B., Bach, A. G. Z., Faria, C. M., Anastásia, S., & Almeida, H. C. de. (2014). Quality of life of patients with strabismus. *Arquivos Brasileiros de Oftalmologia*, 77(2), 110–113. <https://doi.org/10.5935/0004-2749.20140027>
- Ritchie, A., Colapinto, P., & Jain, S. (2013). The psychological impact of strabismus: Does the angle really matter? *Strabismus*, 21(4), 203–208. <https://doi.org/10.3109/09273972.2013.833952>
- Rycroft-Malone, J., Seers, K., Titchen, A., Harvey, G., Kitson, A., & McCormack, B. (2004). What counts as evidence in evidence-based practice? *Journal of Advanced Nursing*, 47(1), 81–90. <https://doi.org/10.1111/j.1365-2648.2004.03068.x>
- Sah, S. P. (2017). Health-Related Quality of Life (HRQoL) in Young Adults with Strabismus in India. *Journal of Clinical and Diagnostic Research*. <https://doi.org/10.7860/JCDR/2017/24541.9389>
- Sandercoe, T. M., Beukes, S., & Martin, F. (2014). Adults with strabismus seek surgery for psychosocial benefits. *Taiwan Journal of Ophthalmology*, 4(1), 17–20. <https://doi.org/10.1016/j.tjo.2013.10.004>
- Scott, A. (2013). Ethical principles in health care research. In E. A. Curtis & J. Drennan (Eds.), *Quantitative health research: Issues and methods* (1st ed.). McGraw-Hill Education.



- Senra, H., Vieira, C. R., Nicholls, E. G., & Leal, I. (2013). Depression and experience of vision loss in group of adults in rehabilitation setting: Mixed-methods pilot study: *Journal of Rehabilitation Research & Development. Journal of Rehabilitation Research & Development*, 50(9), 1301–1313. <https://doi.org/10.1682/JRRD.2012.08.0138>
- Sim, P. Y., Cleland, C., Dominic, J., & Jain, S. (2018). Investigation of factors associated with the success of adult strabismus surgery from the patient's perspective. *Journal of AAPOS: The Official Publication of the American Association for Pediatric Ophthalmology and Strabismus*, 22(4), 266–271.e3. <https://doi.org/10.1016/j.jaapos.2018.03.006>
- Sintonen, H. (2001). The 15D instrument of health-related quality of life: Properties and applications. *Annals of Medicine*, 33(5), 328–336. <https://doi.org/10.3109/07853890109002086>
- Tabachnick, B. G., & Fidell, L. S. (2014). *Using multivariate statistics* (6th ed). Pearson Education.
- TENK. (2023). *The Finnish Code of Conduct for Research Integrity and Procedures for Handling Alleged Violations of Research Integrity in Finland*. Guideline of the Finnish National Board on Research Integrity (TENK) [Guideline].
- Thuma, T. B. T., Gunton, M., Zhang, Q. (Ed), Sharpe, J., & Gunton, K. B. (2023). Is There Gender Bias in Perceptions of Strabismus Among Adults? *Journal of Pediatric Ophthalmology & Strabismus*, 60(6), 396–401. <https://doi.org/10.3928/01913913-20221025-01>
- Thurston, M. (2010). An inquiry into the emotional impact of sight loss and the counselling experiences and needs of blind and partially sighted people: Counselling & Psychotherapy Research. *Counselling & Psychotherapy Research*, 10(1), 3–12. <https://doi.org/10.1080/14733140903492139>
- Valente, S. M. (2004). Visual Disfigurement and Depression. *Plastic Surgical Nursing*, 24(4).
- van de Graaf, E. S., Borsboom, G. J. J. M., van der Sterre, G. W., Feliuz, J., Simonsz, H. J., & Kelderman, H. (2017). Differences in quality-of-life dimensions of Adult Strabismus Quality of Life and Amblyopia & Strabismus Questionnaires. *Graefes Archive for Clinical and Experimental Ophthalmology*, 255(9), 1851–1858. <https://doi.org/10.1007/s00417-017-3694-x>
- van de Graaf, E. S., Feliuz, J., van Kempen-du Saar, H., Looman, C. W. N., Passchier, J., Kelderman, H., & Simonsz, H. J. (2009). Construct validation of the Amblyopia and Strabismus Questionnaire (A&SQ) by factor analysis. *Graefes Archive for Clinical and Experimental Ophthalmology*, 247(9), 1263–1268. <https://doi.org/10.1007/s00417-009-1112-8>
- van de Graaf, E. S., van der Sterre, G. W., Polling, J. R., van Kempen, H., Simonsz, B., & Simonsz, H. J. (2004). Amblyopia & Strabismus Questionnaire: Design and initial validation. *Strabismus*, 12(3), 181–193. <https://doi.org/10.1080/09273970490491196>
- van de Graaf, E. S., van der Sterre, G. W., van Kempen-du Saar, H., Simonsz, B., Looman, C. W. N., & Simonsz, H. J. (2007). Amblyopia and Strabismus Questionnaire (A&SQ): Clinical validation in a historic cohort. *Graefes Archive for Clinical and*

- Experimental Ophthalmology*, 245(11), 1589–1595. <https://doi.org/10.1007/s00417-007-0594-5>
- van der Aa, H. P. A., van Rens, G. H. M. B., Comijs, H. C., Margrain, T. H., Gallindo-Garre, F., Twisk, J. W. R., & van Nispen, R. M. A. (2015). Stepped care for depression and anxiety in visually impaired older adults: Multicentre randomised controlled trial. *BMJ: British Medical Journal*, 351 b6127. <https://doi.org/10.1136/bmj.b6127>
- Vet, H. C. W. de, Terwee, C. B., Mokkink, L. B., & Knol, D. L. (2011). *Measurement in medicine: A practical guide*. Cambridge University Press.
- Vianya-Estopa, M., Elliott, D. B., & Barrett, B. T. (2010). An evaluation of the Amblyopia and Strabismus Questionnaire using Rasch analysis. *Investigative Ophthalmology & Visual Science*, 51(5), 2496–2503. <https://doi.org/10.1167/iovs.09-4381>
- Wang, J. Y., Leske, D. A., Hatt, S. R., & Holmes, J. M. (2019). Diplopia after strabismus surgery for adults with nondiplopic childhood-onset strabismus. *Journal of AAPOS: The Official Publication of the American Association for Pediatric Ophthalmology and Strabismus*, 23(6), 313.e1-313.e5. <https://doi.org/10.1016/j.jaapos.2019.07.005>
- Wang, Z., Ren, H., Frey, R., Liu, Y., Raphael, D., Bian, W., & Wang, X. (2014). Comparison of the Adult Strabismus Quality of Life Questionnaire (AS-20) with the Amblyopia and Strabismus Questionnaire (ASQE) among adults with strabismus who seek medical care in China. *BMC Ophthalmology*, 14(1), 139–139. <https://doi.org/10.1186/1471-2415-14-139>
- Wang, Z., Zhou, J., Luo, X., Xu, Y., She, X., Chen, L., Yin, H., & Wang, X. (2015). Rasch Analysis of the Adult Strabismus Quality of Life Questionnaire (AS-20) among Chinese Adult Patients with Strabismus. *PloS One*, 10(11), e0142188. <https://doi.org/10.1371/journal.pone.0142188>
- Wang, Z., Zhou, J., Xu, Y., Yin, H., She, X., Bian, W., & Wang, X. (2018). Development of a conceptual model regarding quality of life in Chinese adult patients with strabismus: A mixed method. *Health & Quality of Life Outcomes*, 16(1), N.PAG-N.PAG. <https://doi.org/10.1186/s12955-018-0991-y>
- Wang, Z.-H., Bian, W., Ren, H., Frey, R., Tang, L.-F., & Wang, X.-Y. (2013). Development and application of the Chinese version of the adult strabismus quality of life questionnaire (AS-20): A cross-sectional study. *Health & Quality of Life Outcomes*, 11(1), 180–180. <https://doi.org/10.1186/1477-7525-11-180>
- Watkinson, S., & Williamson, S. N. (2023). Introduction. In S. Watkinson & S. N. Williamson (Eds.), *Ocular disease and sight loss: Meeting psychosocial needs* (1st ed.). Springer International Publishing.
- Wild, D., Grove, A., Martin, M., Eremenco, S., McElroy, S., Verjee-Lorenz, A., & Erikson, P. (2005). Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) Measures: Report of the ISPOR Task Force for Translation and Cultural Adaptation. *Value in Health*, 8(2), 94–104. <https://doi.org/10.1111/j.1524-4733.2005.04054.x>
- Williams, M., Wiggins, R., & Vogt, P. R. (2021). *Beginning Quantitative Research*. SAGE Publications Ltd. <https://doi.org/10.4135/9781529682809>

- Williamson, S. N., Seewoodhary, R., & Watkinson, S. (2023). The Psychosocial Impact of Ocular Disease on Body Image. In S. Watkinson & S. N. Williamson (Eds.), *Ocular Disease and Sight Loss: Meeting Psychosocial Needs* (1st ed.). Springer International Publishing.
- WMA. (2013). World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects. *JAMA*, *310*(20), 2191. <https://doi.org/10.1001/jama.2013.281053>. Accessed: 19<sup>th</sup> December 2023.
- Wu, A. C. L., & Choy, B. N. K. (2023). Psychological interventions to reduce intraocular pressure (IOP) in glaucoma patients: A review. *Graefe's Archive for Clinical and Experimental Ophthalmology*, *261*(5), 1215–1227. <https://doi.org/10.1007/s00417-022-05912-2>
- Xu, J., Yu, X., Huang, Y., Chen, J., Yu, H., Wang, Y., & Zhang, F. (2012). The psychosocial effects of strabismus before and after surgical correction in Chinese adolescents and adults. *Journal of Pediatric Ophthalmology and Strabismus*, *49*(3), 170–175. <https://doi.org/10.3928/01913913-20110920-02>
- Xu, M., Yu, H., Chen, Y., Xu, J., Zheng, J., & Yu, X. (2016). Long-Term Quality of Life in Adult Patients with Strabismus after Corrective Surgery Compared to the General Population. *PloS One*, *11*(11), e0166418. <https://doi.org/10.1371/journal.pone.0166418>
- Yao, J., Qu, X., Lin, J., & Liu, H. (2019). Does successful surgical correction of childhood large angle exotropia in adults make any difference to binocularity and quality of life? *Strabismus*, *27*(3), 149–155. <https://doi.org/10.1080/09273972.2019.1643895>
- Yu, H., Yang, X., Ye, T., Chen, J., Zhang, F., & Yu, X. (2013). Development and evaluation of a Chinese version of the Adult Strabismus Questionnaire (AS-20). *Ophthalmic Epidemiology*, *20*(4), 239–247. <https://doi.org/10.3109/09286586.2013.809771>
- Zhang, M., Zhang, C., Chen, C., Liu, L., Liang, Y., Hong, Y., Chen, Y., & Shi, Y. (2023). The experience of diabetic retinopathy patients during hospital-to-home full-cycle care: A qualitative study: BMC Nursing. *BMC Nursing*, *22*(1), 1–10. <https://doi.org/10.1186/s12912-023-01206-y>
- Zhang, X., Wang, S., Du, Z., Seth, I., Wang, Y., Liang, Y., Wu, G., Huang, Y., Liu, S., Hu, Y., Shang, X., Hu, Y., Zhu, Z., & Yu, H. (2023). The associations and mediators between visual disabilities and anxiety disorders in middle-aged and older adults: A population-based study. *American Psychologist*, *78*(8), 982–994. <https://doi.org/10.1037/amp0001143>
- Zhao, B.-W., Fu, J., Wang, J.-H., Bai, H.-X., Liu, P.-P., Guo, Y.-N., Zhang, R.-H., & Su, H. (2021). Quality of life in adult intermittent exotropia and the risk factors. *International Journal of Ophthalmology*, *14*(3), 442–447. <https://doi.org/10.18240/ijo.2021.03.18>

# APPENDICES

# PUBLICATION

I

## **Health-related quality of life in adult patients with strabismus- Translation and psychometric testing of the Adult Strabismus Questionnaire (AS-20) into Finnish**

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Article

# Health-Related Quality of Life in Adult Patients with Strabismus—Translation and Psychometric Testing of the Adult Strabismus Questionnaire (AS-20) into Finnish

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**Abstract:** (1) Strabismus has an impact on individuals' health-related quality of life. The impact should be assessed with valid patient-reported outcome measures such as the Adult Strabismus Questionnaire (AS-20). The AS-20 was further refined using a Rasch analysis for the American population. The aims of the study were to translate and culturally adapt the AS-20 into Finnish and to evaluate the psychometric properties of the Finnish AS-20. (2) The guidelines of the Professional Society for Health Economics and Outcomes Research steered the process and four items were added from the original data as Finnish additions. The construct and convergent validity and internal consistency were evaluated via psychometric testing for three potential Finnish AS-20 structures. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist was applied. (3) The participants ( $n = 137$ ) reported that the translation was clear and understandable. All structures showed high reliability and internal consistency as measured using Cronbach alpha values. The convergent validity assessed using Spearman's correlation coefficients between the structures and one item of Satisfaction with Life Scale indicated very low to moderate positive correlations. The construct validity evaluated using a confirmatory factor analysis revealed the refined AS-20 structure to be satisfactory. (4) The refined AS-20 can be used in clinical practice and research, but further validation is recommended.

**Keywords:** adult strabismus questionnaire AS-20; health-related quality of life; ophthalmic nursing; strabismus; instrument validation



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## 1. Introduction

Strabismus is an ophthalmic condition where the eyes do not point in the same direction and a person struggles to focus their eyes on the same point. The eyes might deviate inwards, outwards, upwards or downwards. The eyes might also rotate inwards or outwards. This condition can also alternate in different directions or be intermittent, visible (tropia) or non-visible (phoria). Strabismus is present in all age groups, and approximately four percent of the adult population globally have this ocular condition [1,2]. Four percent equates to over 200 million adults globally when considering the 2019 United Nations Population Prospects for over 20-year-olds, so strabismus is not a minor ocular condition [3].

Strabismus impacts health-related quality of life (HRQOL) both functionally and psychosocially [4–7]. Everyday physical functioning may be impacted through diplopia (double vision), visual confusion, eye fatigue (asthenopia) and a lack of depth perception. Therefore, driving, working, general functioning and hobbies requiring clear sight might be difficult [4]. Psychosocially, individuals might have trouble in interactions and interpersonal relationships or feel general embarrassment due to the condition. Feelings of social phobia, anxiety, avoidance and depression have also been reported [7–9]. Complaints

of ocular pain due to strabismus are common, and the condition can cause head, back and neck pain due to assuming awkward head positions for better vision [4–6]. All of these factors impact an individual's HRQOL, which consists of mental, physical and social well-being [10].

HRQOL among strabismic adults can be evaluated with generic quality of life measures, but those are not sensitive enough to assess functional struggles with vision or psychosocial challenges that individuals with strabismus exhibit. Therefore, condition-specific instruments are recommended [11].

The AS-20 was developed in the USA and is based on qualitative interviews on the influence of strabismus on an individual's HRQOL [2]. The interviews generated 181 items that were piloted on adult strabismus patients. Items with low or high response rates or a focus purely on symptoms were removed. Item bias was considered by removing items possibly discriminative to some patients (i.e., driving or economic status). The original AS-20 has 20 items divided into psychosocial (items 1–10) and functional (items 11–20) subscales, and HRQOL is measured using a 5-point Likert scale (never, rarely, sometimes, often and always). Individuals choose the option which best reflects the impact of strabismus on their HRQOL, and the responses are calculated as points, where never scores 100, rarely 75, sometimes 50, often 25 and always 0 points. The overall value of HRQOL is calculated by the mean sum of completed items, and a low overall score indicates low HRQOL [2]. Median scores (Md) of visually normal adults have been reported higher with overall (Md 98), psychosocial (Md 100) and functional (Md 95) HRQOL compared to strabismic adults (Md 56, Md 73 and Md 40, respectively) [2].

The original AS-20 is a valid and sensitive tool with good discriminative validity to measure HRQOL for strabismic adults, and its' internal consistency, on the whole measure and for both subscales, has been proven to be high by its Cronbach alfa  $>0.90$  [2]. The AS-20 is also responsive to changes in HRQOL, such as after strabismus surgery, and has good test-re-test ability [12,13].

The original AS-20 was further refined by a Rasch analysis indicating that four subscales rather than two were more accurate to assess HRQOL in the American population. Two items from the functional subscale (items 14 and 19) are not scored in the refined AS-20. A patient's HRQOL is assessed using subscales of self-perception (items 1–4, 6), interaction (items 5, 7–10), reading function (items 12–13, 16, 20) and general function (items 11, 15, 17–18). Additionally, response options of never and rarely are combined in the scoring of the general function subscale. The HRQOL is calculated using the provided look-up table or by computing the means of all completed items separately for each of the four subscales [14]. In the refined AS-20, the self-perception and the reading function subscales are reported to be reliable, whereas the reliability of the interaction and general function subscales is reported to be less than optimal [14].

The impacts of strabismus are seen in ophthalmic departments around the world. The treatments include surgical and non-surgical care options, such as prism glasses and orthoptic exercises [9]. In some countries with socialized healthcare, adults who suffer merely psychosocial impacts from strabismus might not receive surgical treatment, as the surgery is seen as a cosmetic procedure and is not available through the healthcare system [1]. The treatment should be available regardless of the impact of strabismus [1]. Therefore, patient-reported outcome measures should be utilized to aid in clinical decision-making and to improve care [15]. Nurses have a particular role in developing patients' holistic care [16] and should be active in developing care processes for strabismus patients' welfare.

To our knowledge, there has been no specific instrument available to measure HRQOL among Finnish adults with strabismus. Therefore, the aim of this study was to translate and culturally adapt the AS-20 into the Finnish language and culture, and to evaluate the psychometric properties and the descriptive statistics of the Finnish AS-20.



## 2. Materials and Methods

### 2.1. Design

A cross-sectional prospective study was performed to (1) translate and culturally adapt the AS-20 into Finnish and (2) to evaluate the psychometric properties and the descriptive statistics of the Finnish AS-20. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines steered the presentation of this study and the results (Supplementary File S1).

AS-20 is in the public domain. The original developers were contacted regarding the translation and validation process in 2019, and permission was received to use some of the original 181 items for cultural adaptation [17]. The original AS-20 does not have items that reflect common complaints of Finnish strabismic adults such as walking up and down steps, walking on uneven surfaces, playing sports or using mobile devices. Therefore, the authors (L.L., A.M.) chose potential items from the original 181 items [17] to reflect Finnish patients' experiences and consulted a multi-professional team for their clinical experiences of strabismic patient care. Four items were chosen and confirmed by the rest of the research team (K.J., A.K., N.F., A.R.) as relevant to the Finnish culture and context. These four items were added as Finnish additions to the questionnaire for cultural adaptation. The items were: "I find it difficult to go up and down steps", "I have problems walking on uneven surfaces" and "It is difficult for me to play sports because of my eyes" [17]. As our society is very dependent on smart devices and their use has increased since the original questionnaire was developed, an item was modified from "I have problems looking at a computer screen" [17] to "It's difficult for me to use mobile devices because of my eyes". These items are not specific to Finnish culture but are commonly reported by Finnish strabismic adults as functional impacts of strabismus. The use of the Finnish additions could enrich the AS-20 questionnaire in other clinical environments with similar socio-cultural contexts.

### 2.2. Instruments

The demographic background questions included the year of birth, sex and highest level of education (comprehensive school, diploma, bachelor's or master's degree, licentiate or PhD). The strabismus-related background variables included the presence (one, both eyes or not sure) and visibility (yes/no) of the strabismus, impact of the strabismus on work (no; yes partly; yes fully; I am not working), tiredness of the eyes (yes/no), presence of diplopia (yes/no/not sure), need for near vision for work or hobbies (yes/no) and number of strabismus surgeries.

Global life satisfaction was measured by one item of the Satisfaction with Life Scale (SWLS), "I am satisfied with my life". The Finnish SWLS uses a 5-point Likert scale, as the original English SWLS contains response options that are too close in the Finnish language. In the Finnish SWLS, the response options are "fully disagree, partly disagree, neither disagree nor agree, partly agree and fully agree" [18,19].

The first author (A.M.) contacted the developers of the AS-20 [2] to understand the scoring and structure of the AS-20, and the use of a refined AS-20 was recommended. As it was not known how the AS-20 performs in the Finnish population, it was important also to evaluate the psychometric properties of the original valid AS-20 structure. Gothwal et al. [20], in their translation and validation of the AS-20 in India, recommended that the validity of the AS-20 should be evaluated prior to making changes regarding the subscales of the AS-20, as strabismic populations vary in their clinical and background characteristics. Additionally, as the original AS-20 was missing culturally important items, four Finnish additional items were added as described here. Therefore, this study assessed three potential structures and scoring for the Finnish AS-20, which were the original AS-20, the original AS-20 with Finnish additions items and the refined AS-20. To our knowledge, the inclusion of the items from the original data has not been studied before.

### 2.3. Translation Process

The translation and cultural adaptation process followed the guidelines recommended by The Professional Society for Health Economics and Outcomes Research [21]. All items were first forward-translated into Finnish by two researchers (A.M., L.L.) and the translation was assessed by the research group, including researchers from the fields of nursing science, statistics and medicine. All members of the research group were native Finnish speakers and fluent in the English language. During the discussions, some minor changes were conducted, such as for item 5 “People do not give me opportunities because of my eyes” an explanation of “for example in the working life” was added, and for the item 16 “I have problems reading because of my eye condition” was changed from “Due to my eye condition it is difficult for me to read” to “The state of my eyes makes reading more difficult”. After the changes, an agreement was reached on the forward translation and the first Finnish version of the AS-20 was approved. It was then sent to five native Finnish speaking adults for cognitive debriefing and comments were requested on the clarity and fluency of the forward translation [21]. They reported the translation to be clear and comprehensible, but a few corrections were suggested regarding Finnish grammar and re-wording, changing item 10 from “I find it hard to initiate contact with people I don’t know because of my eyes” to “Because of my eyes it’s hard for me to take the initiative or to make contact with people I don’t know”. The corrections were discussed in the research team and agreed upon and the instrument was changed accordingly.

Next, the Finnish AS-20 was back-translated into English by a professional interpreter and afterwards compared to the original English AS-20 by the research team. Even though all items were not literally identical, the meaning was the same. Therefore, the Finnish version of AS-20 was approved by the research group for pilot testing.

### 2.4. Participants and Data Collection

This study was conducted in a university hospital’s ophthalmology clinic in Finland caring for people with strabismus. In 2019, there were 3400 strabismus outpatient visits and nearly 350 strabismus surgeries performed. The data collection began in December 2019 and finished in December 2020. The COVID pandemic slowed the data collection as the number of patients attending the outpatient clinic was reduced due to the pandemic.

There are no universally accepted guidelines for sample sizes for validation studies, and the minimum numbers vary [22]. In this study, the sample size was calculated as requiring 5 subjects per item to achieve a minimum of 120 participants [23]; therefore, a total of 150 participants with visible strabismus or symptomatic phoric patients were recruited to prepare for possible losses in participation. The criteria for participation were the following: adult (18+ years) patients in the ophthalmology clinic, fluent in Finnish, without cognitive impairments or critical conditions affecting HRQOL. As the aim was to validate an instrument measuring HRQOL, participants with severe conditions, including patients with thyroid eye disease, heart or brain infarcts and other severe somatic or psychiatric illnesses were excluded. Patients who had received recent surgery were also excluded, as side effects from the surgery could have affected their HRQOL. To achieve the limitation, two researchers (A.M., L.L.) marked in advance potential patients coming to the clinic so that the staff could offer them purposeful participation in the study. The patients were given an information letter regarding the study on arrival and the staff checked the participation criteria. The patients were told that participation was voluntary and would not alter their care. Written consent was obtained from all participants.

A total of 150 participants consented to the study. They were given a postage paid envelope that contained a questionnaire with background questions and the translated AS-20 with Finnish additions. They could fill in the questionnaire independently in the clinic or at home, and could then return it to the researchers. Questionnaires were returned by 138 patients. One of the participants was found to have a severe long-term illness, so one questionnaire was left out of the analysis. The data for a total of 137 participants were analyzed.

## 2.5. Data Analysis

The data on the participants' demographic and strabismus-related variables, satisfaction with life and HRQOL sum scales were described using frequencies and percentages for qualitative variables and the mean (M), standard deviation (SD), median (Md) and quartiles (Q1, Q3) for quantitative variables. Participant responses for the original AS-20 and AS-20 with Finnish additions were calculated as points, whereby never scored 100 points, rarely 75, sometimes 50, often 25 and always 0 points [2]. For the refined AS-20 structure, the descriptive statistics were calculated both by computing the mean of all completed items separately for each four subscales (clinical use) and by using the provided look-up table [14]. This was to compare whether there was a difference in Finnish participants' mean sums when the scores were calculated using either a 5-point scale (clinical use, options of never, rarely, sometimes, often, always) or a 4-point scale (look-up table), where in the general function subscale "never" and "rarely" are combined as one option.

All statistical analyses evaluating the psychometric properties of the Finnish AS-20 were conducted on three different structures: (1) for the whole original AS-20 measure and its' two subscales; (2) for the original AS-20 measure with Finnish additions; (3) for the refined AS-20 with four subscales. The psychometric properties evaluated were the internal consistency, construct validity and convergent validity. The data were analyzed using IBM SPSS Statistics version 25 and a confirmatory factor analysis (CFA) was performed on MPlus 8.5. Statistical significance was set at  $p < 0.05$  [24].

### 2.5.1. Internal Consistency

The internal consistency describes how well the items of an instrument evaluate the same construct. In this study, internal consistency was calculated using Cronbach alpha values ( $\alpha$ ), as all items on the AS-20 evaluate HRQOL. The calculations were conducted separately on overall scores for the AS-20 and AS-20 with Finnish additions and their subscale scores, and for the refined AS-20 subscales. The lowest acceptable value was set to be 0.70 [25].

### 2.5.2. Convergent Validity

The convergent validity is assessed by testing if the instrument used for validation has an association with another instrument measuring similar constructs. As there are no validated measures to evaluate HRQOL among Finnish strabismic adults, the convergent validity was tested by calculating Spearman correlation coefficients between one item ("I am satisfied with life") of the Satisfaction with Life Scale (SWLS) with overall scores for the AS-20 and AS-20 with Finnish additions and their subscale scores, and for the refined AS-20 subscales. Spearman's correlation coefficient was selected because the items from the SWLS scale were of an ordinal scale and the distributions of the sums of AS-20 subscales were skewed. Values of 0.20–0.49 were defined as having a low correlation, 0.50–0.69 as moderate, 0.70–0.89 as high and 0.90–1.00 as very high [26].

### 2.5.3. Construct Validity

The construct validity is the degree to which the evaluated instrument measures the studied construct and how the instrument provides scores based on previous knowledge or theory. In this study, the CFA was used to assess the construct validity, as the English AS-20 was already shown to validly assess HRQOL among strabismic adults [25–27]. Different fit indices were examined to assess the fit of the three potential Finnish structures of the AS-20, including the chi-square goodness of fit, root mean square error of approximation (RMSEA), standardized root mean square residual (SRMR), Comparative Fit Index (CFI) and Tucker–Lewis Index (TLI). Cut-off values close to 0.95 were used for the CFI and TLI, 0.08 for the SRMR and 0.06 for the RMSEA [27,28]. A non-significant chi-square value was an indication of a good fit [29]. The CFA models for the three Finnish structures of the AS-20 were estimated using items as categorical variables with the weighted least square mean and variance-adjusted estimation method (WLSMV) [30].

## 2.6. Ethical Considerations

The Declaration of Helsinki and national guidelines for responsible research conduct were followed [31,32]. The ethical board of the healthcare organization approved the study and permission was granted. Participation in the study was voluntary and did not alter the care for the participating patients, who all gave written informed consent. The participants were informed that they could discontinue their participation at any stage of the study. Confidentiality was maintained and the organization's data policy was followed.

## 3. Results

### 3.1. Participants

All participants filled in the questionnaire independently, either in the clinic or at home, and posted it to the researchers. The response rate for this study was 91%. More than half of the study participants were women (59%,  $n = 81$ ) and over three-quarters had either a vocational diploma or degree (78%,  $n = 107$ ). The age range of the participants matched the age range of the adult patients in the clinic, as the youngest participant was 18 and the oldest were 84 years old ( $M = 47$ ,  $SD = 17$ ). One-third of the participants (30%,  $n = 41$ ) reported not to be working.

Over half of the participants reported having strabismus purely on one eye (55%,  $n = 75$ ) and over three-quarters (79%,  $n = 107$ ) described their strabismus as being visible. Tiredness of the eyes was a very common symptom for the participants (89%,  $n = 122$ ), and nearly two-thirds reported suffering from diplopia (63%,  $n = 86$ ). Nearly all reported needing near vision for work or hobbies (97%,  $n = 133$ ). Half of the patients (52%,  $n = 71$ ) communicated that the strabismus had a partial influence on their work, but they managed in their own job. Regarding surgery, nearly half of the patients (44%,  $n = 60$ ) had had at least one surgery.

Table 1 presents the participants' background variables and strabismus-related characteristics.

**Table 1.** The participants' self-reported characteristics,  $n = 137$ .

Background Variables	<i>n</i>	%
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
Highest education		
Comprehensive	23	16.9
Diploma	44	32.4
Degree	63	46.3
Licentiate or PhD	6	4.4
Strabismus related variables		
Presence of strabismus		
One eye	75	54.7
Both eyes	55	40.1
Not sure	6	4.4
Is strabismus visible		
Yes	107	78.7
No	29	21.3
Tiredness of eyes		
Yes	122	89.1
No	15	10.9

**Table 1.** *Cont.*

Background Variables	<i>n</i>	%
Double vision (diplopia)		
Yes	86	62.8
No	51	37.2
Do you need near vision for work/hobbies		
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 my own role	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

### 3.2. Translation and Adaptation Process

Most participants found the translated Finnish AS-20 items to be understandable or extremely understandable (91%,  $n = 124$ ) and the clarity of the questionnaire was assessed by most as very or extremely clear (91%,  $n = 125$ ). Some participants suggested adding more items on ocular pain, discomfort and tiredness ( $n = 11$ ); eye glass usage ( $n = 5$ ), driving ( $n = 5$ ); and psychosocial concerns, particularly regarding pressure related to appearance and social interactions ( $n = 8$ ). The participants ( $n = 8$ ) criticized the response option “never” for items 5 and 19, as this was a double-negative, and recommended changing “never” into “not applicable” or changing the items into positive statements. Additionally, four participants commented on item 14 being unclear and recommended providing an example of depth perception for the item. The participants also expressed joy in the questionnaire ( $n = 5$ ) that strabismus and its impact on HRQOL is studied in Finnish settings.

The participants’ responses to the AS-20 items varied from never to always, although the option “always” was the least used. Regarding the interactions, it is noteworthy that over half of the participants chose “never” for items 7, 9 and 10 (53%,  $n = 72$ ; 54%,  $n = 74$ ; 56%,  $n = 76$ , respectively), and three-quarters of patients selected “never” for item 5 (75%,  $n = 100$ ). Table 2 shows the AS-20 and Finnish additional items and their frequencies and percentages.

The functional HRQOL of the participants was lower (Md = 53, Q1 = 38, Q3 = 66) than the psychosocial HRQOL with the original AS-20 structure (Md = 75, Q1 = 54, Q3 = 90), whereas with the refined AS-20, the participants’ HRQOL based on the interaction subscale was higher (Md = 88, Q1 = 65, Q3 = 100) than the self-perception subscale (Md = 60, Q1 = 38, Q3 = 85). For the refined AS-20, the sum scores were similar for the three subscales, despite the method of calculation that was used. However, for the general function subscale, the participants’ sum scores were much lower with the clinical use calculation method in comparison to the look-up table (Md = 44, Q1 = 34, Q3 = 59 vs. Md = 60, Q1 = 47, Q3 = 76, respectively).

**Table 2.** Frequencies and percentages of participants’ responses to the translated Adult Strabismus Questionnaire (AS-20) and Finnish additional items ( $n = 137$ ; <sup>†</sup> Hatt et al. [2], Hatt et al. [17]).

	Never		Rarely		Sometimes		Often		Always	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
AS-20 Psychosocial Subscale										
1. I worry about what people will think about my eyes	35	25.5	26	19.0	37	27.0	27	19.7	12	8.8
2. I feel that people are thinking about my eyes when they do not say anything	43	31.4	26	19.0	37	27.0	24	17.5	7	5.1
3. I feel uncomfortable when people are looking at me because of my eyes	40	29.2	23	16.8	42	30.7	21	15.3	11	8.0
4. I wonder what people are thinking when they are looking at me because of my eyes	45	32.8	33	24.1	26	19.0	25	18.2	8	5.8
5. People do not give me opportunities because of my eyes, for example in the working life ( $n = 133$ )	100	75.2	15	11.3	11	8.3	6	4.5	1	0.8
6. I am self-conscious about my eyes	27	19.7	25	18.2	36	26.3	35	25.5	14	10.2
7. People avoid looking at me because of my eyes ( $n = 136$ )	72	52.9	33	24.3	21	15.4	9	6.6	1	0.7
8. I feel inferior to others because of my eyes	61	44.5	30	21.9	28	20.4	13	9.5	5	3.6
9. People react differently to me because of my eyes ( $n = 136$ )	74	54.4	31	22.8	19	14.0	8	5.9	4	2.9
10. I find it hard to initiate contact with people I do not know because of my eyes	76	55.5	22	16.1	15	10.9	18	13.1	6	4.4
AS-20 Functional subscale										
11. I cover or close one eye to see things better	15	10.9	13	9.5	52	38.0	52	38.0	5	3.6
12. I avoid reading because of my eyes	45	32.8	26	19.0	37	27.0	24	17.5	5	3.6
13. I stop doing things because my eyes make it hard to concentrate	30	21.9	36	26.3	50	36.5	19	13.9	2	1.5
14. I have problems with depth perception ( $n = 136$ )	24	17.6	21	15.4	44	32.4	33	24.3	14	10.3
15. My eyes feel strained	8	5.8	4	2.9	43	31.4	70	51.1	12	8.8
16. I have problems reading because of my eye condition	9	6.6	22	16.1	44	32.1	42	30.7	20	14.6
17. I feel stressed because of my eyes	17	12.4	34	24.8	40	29.2	35	25.5	11	8.0
18. I worry about my eyes	11	8.0	19	13.9	50	36.5	44	32.1	13	9.5
19. I cannot enjoy my hobbies because of my eyes	31	22.6	31	22.6	43	31.4	25	18.2	7	5.1
20. I need to take frequent breaks when reading because of my eyes	27	19.7	31	22.6	28	20.4	42	30.7	9	6.6
Finnish additional items										
21. I find it difficult to go up and down steps	50	36.5	30	21.9	31	22.6	12	8.8	14	10.2
22. I have problems walking on uneven surfaces	41	29.9	27	19.7	32	23.4	25	18.2	12	8.8
23. It is difficult for me to play sports because of my eyes	46	33.6	43	31.4	30	21.9	14	10.2	4	2.9
24. I have problems using mobile devices because of my eyes	32	23.4	41	29.9	34	24.8	24	17.5	6	4.4
Satisfaction with Life Scale, Finnish version [19]	<b>Fully disagree</b>		<b>Partly disagree</b>		<b>Neither disagree nor agree</b>		<b>Partly agree</b>		<b>Fully agree</b>	
I am satisfied with my life	4	2.9	29	21.2	3	2.2	55	40.1	46	33.6

Note: <sup>†</sup>  $n$  varies from 133 to 137.

Table 3 presents descriptive the statistics and psychometric properties of all three Finnish AS-20 questionnaire structures and their subscales.

**Table 3.** Descriptive statistics and psychometric properties of the three Finnish AS-20 structures and their subscales ( $n = 137$ ).

	Mean (SD) §		Median (Q1, Q3) §		Cronbach Alfa $\alpha^{\dagger}$	Spearman's $r$ Coefficient $\ddagger$
AS-20 original (items 1–20)	60.8 (18.0)		63.8 (48.8, 72.5)		0.919	0.501
AS-20 original psychosocial subscale (items 1–10)	70.0 (24.7)		75.0 (53.8, 90.0)		0.953	0.459
AS-20 original functional subscale (items 11–20)	51.6 (19.1)		52.5 (37.5, 66.3)		0.871	0.318
AS-20 with Finnish additions (items 1–24)	61.5 (17.4)		63.5 (52.0, 74.0)		0.923	0.474
Finnish additional items (items 21–24)	65.1 (25.8)		68.8 (50.0, 87.5)		0.858	0.142
	Mean (SD)		Median (Q1, Q3)		Cronbach alfa $\alpha^{\dagger}$	Spearman's $r$ coefficient $\ddagger$
AS-20 refined subscales	Clinical use §	Look-up table	Clinical use §	Look-up table		
AS-20 refined, self-perception subscale SP (items 1–4,6)	60.1 (29.0)	62.5 (28.6)	60.0 (37.5, 85.0)	63.7 (39.9, 87.5)	0.950	0.439
AS-20 refined -interaction subscale IN (items 5, 7–10)	79.9 (22.9)	79.6 (23.1)	87.5 (65, 100)	89.7 (64.4, 100)	0.905	0.456
AS20 refined, reading function subscale RF (items 12–13,16, 20)	56.3 (25.3)	59.9 (25.3)	50.0 (37.5, 78.1)	57.1 (41.8, 81.0)	0.900	0.194
AS20 refined, general function subscale GF (items 11,15,17–18)	44.9 (18.5)	57.8 (21.0)	43.8 (34.4, 59.4)	59.5 (47.0, 75.8)	0.675	0.344

SD = standard deviation; Q1 = lower quartile; Q3 = upper quartile. Note:  $\dagger = n$  varies from 131 to 137;  $\ddagger$  = Spearman correlation coefficient calculated using the item "I am satisfied with my life" from Satisfaction of Life Scale; § = scores calculated by computing the mean of all completed items.

### 3.3. Internal Consistency

The reliability and internal consistency were analyzed separately using the Cronbach alphas for the AS-20 original and AS-20 with Finnish additions, their subscales and the refined AS-20 subscales. The results showed that the overall scores for the original AS-20 and AS-20 with Finnish additions showed high internal consistency and reliability ( $\alpha = 0.919, 0.923$ , respectively). Furthermore, the subscales of the refined AS-20 had strong Cronbach alpha values, except for the general function subscale, which was borderline ( $\alpha = 0.675$ ).

### 3.4. Convergent Validity

Over three-quarters of the study participants were either partly (40%,  $n = 55$ ) or fully (37%,  $n = 46$ ) satisfied with their life, as measured by the item "I am satisfied with my life". Spearman's correlation coefficient showed very low to moderate positive correlations between the item and the overall scores of the original AS-20 and AS-20 with Finnish additions ( $r = 0.501, 0.474$ , respectively). The correlation coefficient for the refined AS-20 was moderate for the self-perception ( $r = 0.439$ ) and interaction subscales ( $r = 0.456$ ), but there was a very low positive correlation between "I am satisfied with my life" and the sum scales of the reading function subscale ( $r = 0.194$ ).

### 3.5. Construct Validity

A CFA was conducted on the three structures of the Finnish AS-20. In the CFA of the original AS-20 and the original with Finnish additions, 131 participants were included, whereas in the CFA of the refined AS-20, 132 participants were included. The chi-square goodness of fit was statistically significant, indicating no fit for all structures, and the RMSEA values were higher than the recommended cut-off value of 0.06 for all structures. The SRMR values were higher than the recommended value of 0.08 for the original AS-20 and original AS-20 with Finnish additions (0.124 and 0.121, respectively), whereas the value for the refined AS-20 structure was acceptable (0.077). The CFI and TLI values for all structures were within the recommended cut-off value range. The model fit indicators for the three structures of the Finnish AS-20 are presented in Table 4.

**Table 4.** The model fit indicators for the three structures of the Finnish AS-20.

Finnish AS-20 Structures and Their Subscales	$\chi^2$	df	<i>p</i>	RMSEA	CFI	TLI	SRMR
AS-20 original ( <i>n</i> = 131, items 1–20)	628.702	169	<i>p</i> < 0.001	0.141	0.949	0.943	0.124
AS-20 with Finnish additions ( <i>n</i> = 131, items 1–24)	814.509	249	<i>p</i> < 0.001	0.129	0.939	0.932	0.121
AS-20 refined ( <i>n</i> = 132, items 1–13, 15–18, 20)	348.089	129	<i>p</i> < 0.001	0.111	0.976	0.971	0.077

$\chi^2$  = The chi-square goodness of fit; df = degrees of freedom; RMSEA = root mean square error of approximation; CFI = Comparative Fit Index; TLI = Tucker–Lewis Index; SRMR = standardized root mean square residual.

#### 4. Discussion

This study aimed to translate and culturally adapt the Adult Strabismus Questionnaire (AS-20) to the Finnish language and culture and to evaluate the psychometric properties and descriptive statistics of the Finnish AS-20. The AS-20 was chosen for validation, as it is a specific measure used for evaluating HRQOL among strabismic adults [2,12].

##### 4.1. Translation and Adaptation Process

The translation process proceeded according to Wild et al. [21]. The developers of the AS-20 were contacted for permission for translation, but also to understand the scoring of the measure to be able to keep the translated AS-20 as close to the original as possible [25]. However, as the measure also needs to be valid culturally [21,25], four additional items, the Finnish additions, were chosen from the original AS-20 development data [17] to present the challenges faced by Finnish strabismic adults. This improved the cultural adaptation, as the measures are aimed toward the target population [25].

The participants in the study were Finnish-speaking adults with strabismus who had attended an outpatient clinic in the search for help for their condition. Purposive sampling with inclusion criteria was used to increase the validity of the measures in the Finnish language and to decrease the risk for other factors than strabismus influencing the HRQOL. The participants for the study reflected the target population the AS-20 is designed for [25].

The participants' comments on the double-negativity on items 5 and 19 were noted. As item 5 also showed very little variation in the participants' response options (75% replied never), the research team considered whether this was due to the item's wording. A decision was made to re-word item 5 from a negative to a positive statement "Because of my eyes my opportunities (for example in the working life) are reduced". As the items 14 and 19 showed greater variation in the responses, the research team decided not to change the wording. For item 14, only four participants mentioned difficulty with the item. It is noteworthy that neither items 14 nor 19 are scored in the refined AS-20 [14].

Item 5 also needed revision in Chinese and Danish translations of the AS-20 [33,34]. In both studies, as in this study, participants commented on problems with driving as an additional factor impacting their HRQOL [33,34]. Item bias was considered in the AS-20 development phase by removing items potentially discriminative to some patients [2]; therefore, problems with driving or eye glass usage are not present in the Finnish AS-20 either. Additionally, the AS-20 aims to evaluate the impact of strabismus on HRQOL, not its symptoms [2]; hence, headache, neck or ocular pain and tiredness are not present in the Finnish AS-20.

In the future, it will be important to assess whether the participants respond differently to item 5 after changing it into a positive statement. It might also be necessary to reduce the number of response options in the Finnish AS-20. However, some of the results regarding interactions or opportunities could be due to the Finnish society of equality and culture for social interactions.

##### 4.2. Psychometric Properties

The internal consistency as assessed by the Cronbach alpha values was high for both the Finnish original AS-20 and AS-20 with Finnish additions. The original AS-20 and its subscales and the Danish and Chinese translations of the instrument have been shown to



have good internal consistency [2,33,34]. The refined structure of the Finnish AS-20 showed good internal consistency for three of its' subscales, while the fourth, the general function, was slightly under the recommended cut-off value (Cronbach  $\alpha = 0.675$ ). Leske et al. [14] reported that interaction and general function subscales have less than optimal reliability. This was only seen for the general function and not the interaction subscale of the Finnish refined AS-20.

The convergent validity as assessed by the correlations between all sum scales of Finnish AS-20 structures and an item of the SWLS measure showed very low to moderate positive correlations. Although the item of SWLS does not directly measure HRQOL but instead measures satisfaction with life, it is noteworthy that the correlations were positive. As there are no translated and validated HRQOL measures for strabismic or ophthalmic patients, the SWLS was chosen. It is also possible that the use of the Finnish SWLS, with a five-point Likert scale rather than a seven-point scale, influenced the results [18,19].

The construct validity values of the three Finnish AS-20 structures were evaluated using the CFA, and the sample size met the recommendations for CFAs [29]. The chi-square values were significant, as were the non-fit model values for all structures, although Tabachnick and Fidell [27] (p. 770) stated that the use of small or large sample sizes might affect the chi-square values. Additionally, if the sample size is small (<250), Hu and Bentler [28] recommend focusing on a combination of the SRMR and CFI values to minimize the error rates. Based on the combination of these two values, the refined AS-20 structure with 18 items and four subscales showed acceptable construct validity for the Finnish AS-20.

Leske et al. [14] recommend the refined AS-20 for research and clinical work. Although they advise using a look-up table to score the measure, it is important to note the difference in the Finnish participants' scores for the general function subscale between the clinical use calculations, where the items were graded using a five-point Likert scale, and the look-up table calculations, where the options of never and rarely were combined. In future research, the method used for score calculations should be considered. As this study has piloted the Finnish additions with the original AS-20 and validates the Finnish AS-20 for only this specific sample and situation, it is necessary to continue the validation process for the Finnish AS-20 [25].

#### 4.3. Strengths and Limitations

The translation of the Finnish AS-20 items was reported to be understandable, clear and showed high acceptability by the participants. The high response rate (91%) shows that studying the impact the strabismus has on HRQOL is also necessary in the Finnish context, and using the patient-reported outcome measure it can be validly measured. These increase the strength of this study.

For cultural adaptation, four additional items were chosen from the raw data [17]. The Finnish additions make the AS-20 more applicable to the target group and improve the clinical use of the instrument [25] and the strength of this study. Although in this study the participants used all response options for the Finnish additional items, the structure of the AS-20 with Finnish additions requires further studying and larger samples to assess whether the experiences of Finnish clinicians can also be seen in wider research results.

There are limitations in this study. Although all Finnish AS-20 structures showed good internal consistency and fair convergent validity, the construct validity was acceptable only for the refined AS-20. This could have been due to the missed responses, the translation of the items or the small sample size used for the CFA. Even though the participants represented the patients in the outpatient clinic well, the sample size was small. As purposive sampling was used to avoid other illnesses than strabismus influencing HRQOL, it is possible that some important patient experiences were missed or highlighted.

## 5. Conclusions

We have provided three structures for the Finnish AS-20 to evaluate the HRQOL among adults with strabismus. In this study sample, the refined AS-20 proved to be the most satisfactory structure for the Finnish AS-20. The Finnish AS-20 is an understandable and clear HRQOL measure for clinical use for Finnish strabismic patients to improve their care. Additional research in this area is recommended to further validate the Finnish AS-20 structure, its clinical utility and the scoring for research use.

**Supplementary Materials:** The following supporting information can be downloaded at: <https://www.mdpi.com/article/10.3390/ijerph20042830/s1>, the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines are attached as Supplementary File S1.

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## References

1. Marsh, I.B. We need to pay heed to the psychosocial aspects of strabismus. *Eye* **2015**, *29*, 238–240. [CrossRef] [PubMed]
2. Hatt, S.R.; Leske, D.A.; Bradley, E.A.; Cole, S.R.; Holmes, J.M. Development of a Quality-of-Life Questionnaire for Adults with Strabismus. *Ophthalmology* **2009**, *116*, 139–144.e5. [CrossRef]
3. United Nations, Department of Economic and Social Affairs, Population Division. World Population Prospects 2019, Custom Data Acquired via Website. 2019. Available online: <https://population.un.org/wpp> (accessed on 24 August 2022).
4. Hatt, S.R.; Leske, D.A.; Kirgis, P.A.; Bradley, E.A.; Holmes, J.M. The Effects of Strabismus on Quality of Life in Adults. *Am. J. Ophthalmol.* **2007**, *144*, 643–647. [CrossRef]
5. McBain, H.B.; MacKenzie, K.A.; Au, C.; Hancox, J.; Ezra, D.G.; Adams, G.G.; Newman, S.P. Factors associated with quality of life and mood in adults with strabismus. *Br. J. Ophthalmol.* **2014**, *98*, 550–555. [CrossRef]
6. Chang, M.Y.; Velez, F.G.; Demer, J.L.; Isenberg, S.J.; Coleman, A.L.; Pineles, S.L. Quality of Life in Adults with Strabismus. *Am. J. Ophthalmol.* **2015**, *159*, 539–544.e2. [CrossRef]
7. Adams, G.G.; McBain, H.; MacKenzie, K.; Hancox, J.; Ezra, D.G.; Newman, S.P. Is strabismus the only problem? Psychological issues surrounding strabismus surgery. *J. AAPOS* **2016**, *20*, 383–386. [CrossRef]
8. Alpak, G.; Coskun, E.; Bez, Y.; Okumus, S.; Oren, B.; Gurler, B. Effects of corrective surgery on social phobia, psychological distress, disease-related disability and quality of life in adult strabismus patients. *Br. J. Ophthalmol.* **2014**, *98*, 876–879. [CrossRef]
9. McBain, H.B.; Au, C.K.; Hancox, J.; MacKenzie, K.A.; Ezra, D.G.; Adams, G.G.; Newman, S.P. The impact of strabismus on quality of life in adults with and without diplopia: A systematic review. *Surv. Ophthalmol.* **2014**, *59*, 185–191. [CrossRef]

10. National Institute for Health and Clinical Excellence (NICE). 2022. Available online: <https://www.nice.org.uk/glossary?letter=h> (accessed on 25 August 2022).
11. Carlton, J.; Kaltenthaler, E. Health-related quality of life measures (HRQoL) in patients with amblyopia and strabismus: A systematic review. *Br. J. Ophthalmol.* **2011**, *95*, 325–330. [CrossRef]
12. Hatt, S.R.; Leske, D.A.; Holmes, J.M. Responsiveness of Health-Related Quality-of-life Questionnaires in Adults Undergoing Strabismus Surgery. *Ophthalmology* **2010**, *117*, 2322–2328.e1. [CrossRef]
13. Leske, D.A.; Hatt, S.R.; Holmes, J.M. Test–Retest Reliability of Health-Related Quality-of-Life Questionnaires in Adults with Strabismus. *Am. J. Ophthalmol.* **2010**, *149*, 672–676. [CrossRef] [PubMed]
14. Leske, D.A.; Hatt, S.R.; Liebermann, L.; Holmes, J.M. Evaluation of the Adult Strabismus-20 (AS-20) Questionnaire using Rasch analysis. *Investig. Ophthalmol. Vis. Sci.* **2012**, *53*, 2630–2639. [CrossRef] [PubMed]
15. Lavalley, D.C.; Chenok, K.E.; Love, R.M.; Petersen, C.; Holve, E.; Segal, C.D.; Franklin, P.D. Incorporating patient-reported outcomes into health care to engage patients and enhance care. *Health Aff.* **2016**, *35*, 575–582. [CrossRef] [PubMed]
16. Persson, U.; Carlson, E. Conceptions of professional work in contemporary healthcare: Perspectives from registered nurses in somatic care: A phenomenographic study. *J. Clin. Nurs.* **2019**, *28*, 201–208. [CrossRef]
17. Hatt, S.R.; Leske, D.A.; Holmes, J.M. Patient-derived questionnaire items for patient-reported outcome measures in adults with strabismus. *J. AAPOS* **2019**, *23*, 100–101.e3. [CrossRef]
18. Diener, E.; Emmons, R.A.; Larsen, R.J.; Griffin, S. The Satisfaction with Life Scale. *J. Pers. Assess.* **1985**, *49*, 71–75. [CrossRef]
19. Backman, K.; Hentinen, M. Factors associated with the self-care of home-dwelling elderly. *Scand. J. Caring Sci.* **2001**, *15*, 195–202. [CrossRef]
20. Gothwal, V.K.; Bharani, S.; Kekunnaya, R.; Chhablani, P.; Sachdeva, V.; Pehera, N.K.; Narasaiah, A.; Gunturu, R. Measuring Health-Related Quality of Life in Strabismus: A Modification of the Adult Strabismus-20 (AS-20) Questionnaire Using Rasch Analysis. *PLoS ONE* **2015**, *10*, e0127064. [CrossRef]
21. Wild, D.; Grove, A.; Martin, M.; Eremenco, S.; McElroy, S.; Verjee-Lorenz, A.; Erikson, P.; ISPOR Task Force for Translation and Cultural Adaptation. Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) Measures: Report of the ISPOR Task Force for Translation and Cultural Adaptation. *Value Health* **2005**, *8*, 94–104. [CrossRef]
22. Anthoine, E.; Moret, L.; Regnault, A.; Sébille, V.; Hardouin, J.B. Sample size used to validate a scale: A review of publications on newly-developed patient reported outcomes measures. *Health Qual. Life Outcomes* **2014**, *12*, 176. [CrossRef]
23. Hair, J.F.; Tatham, R.L.; Anderson, R.E.; Black, W. *Multivariate Data Analysis*, 5th ed.; Prentice Hall: Upper Saddle River, NJ, USA, 1998.
24. Duffy, M.E.; Munro, B.H.; Jacobsen, B.S. Key principles of Statistical Inference. In *Statistical Methods for Health Care Research*, 5th ed.; Munro, B.H., Ed.; Lippincott Williams & Wilkins: Philadelphia, PA, USA, 2005; pp. 73–105.
25. De Vet, H.C.W.; Terwee, C.B.; Mokkink, L.B.; Knol, D.L. *Measurement in Medicine: A Practical Guide*; Cambridge University Press: Cambridge, UK, 2011.
26. Munro, B.H. Correlation. In *Statistical Methods for Health Care Research*, 5th ed.; Munro, B.H., Ed.; Lippincott Williams & Wilkins: Philadelphia, PA, USA, 2005; pp. 239–258.
27. Tabachnick, B.G.; Fidell, L.S. *Using Multivariate Statistics*, 6th ed.; Pearson Education Limited: Harlow, UK, 2014; pp. 660–836.
28. Hu, L.; Bentler, P.M. Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Struct. Equ. Model.* **1999**, *6*, 1–55. [CrossRef]
29. Aroian, K.J.; Norris, A.E. Confirmatory factor analysis. In *Statistical Methods for Health Care Research*, 5th ed.; Munro, B.H., Ed.; Lippincott Williams & Wilkins: Philadelphia, PA, USA, 2005; pp. 351–375.
30. Xia, Y.; Yang, Y. RMSEA, CFI, and TLI in structural equation modeling with ordered categorical data: The story they tell depends on the estimation methods. *Behav. Res. Methods* **2018**, *51*, 409–428. [CrossRef]
31. World Medical Association. Declaration of Helsinki—Ethical Principles for Medical Research Involving Human Subjects. 2018. Available online: <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/> (accessed on 25 August 2022).
32. Finnish National Board on Research Integrity TENK. Responsible Conduct of Research and Procedures for Handling Allegations of Misconduct in Finland. *Guidelines of the Finnish Advisory Board on Research Integrity*. 2012. Available online: <https://tenk.fi/en/advice-and-materials> (accessed on 25 August 2022).
33. Yu, H.; Yang, X.; Ye, T.; Chen, J.; Zhang, F.; Yu, X. Development and Evaluation of a Chinese Version of the Adult Strabismus Questionnaire (AS-20). *Ophthalmic Epidemiol.* **2013**, *20*, 239–247. [CrossRef] [PubMed]
34. Ali, N.; Sørensen, M.S.; Sørensen, T.L.; Mortzos, P. Evaluation and validity of the Danish version of the Adult Strabismus Questionnaire AS-20. *Clin. Ophthalmol.* **2016**, *10*, 65–69. [CrossRef] [PubMed]

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**PUBLICATION**  
**II**

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

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## ORIGINAL ARTICLE

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

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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-subscores 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).

Background variables	<i>n</i>	%
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		
Presence of strabismus		
One eye	75	54.7
Both eyes	55	40.1
Not sure	6	4.4
Is strabismus visible		
Yes	107	78.7
No	29	21.3
Tiredness of eyes		
Yes	122	89.1
No	15	10.9
Experienced diplopia		
Yes	86	62.8
No	51	37.2
Do you need near vision for work/hobbies		
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 my own role	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
Not measured	98	71

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.

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

Experienced diplopia ( $n=137$ )	Binocularity distance viewing ( $n=134$ )			Binocularity near viewing ( $n=134$ )		
	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 ( $n=51$ )	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 ( $n=44$ )	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 ( $n=6$ )	70.0	30–80		100	75–100		59.4	12.5–87.5		43.8	12.5–68.8	
Previous strabismus surgery												
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 diplopia ( $n=137$ )												
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.

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	<i>p</i> Value	Md	Range	<i>p</i> Value	Md	Range	<i>p</i> Value	Md	Range	<i>p</i> Value
Binocular function distance ( $n=134$ )												
NRC ( $n=42$ )	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 ( $n=134$ )												
NRC ( $n=52$ )	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% $n=21$ )	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% $n=26$ )	52.5	0–100		77.5	10–100		50.0	18.8–93.8		37.5	0–38.8	
Exotropia and vertical strabismus (39% $n=54$ )	60.0	0–100		88.8	20–100		59.4	0–100		43.8	6.3–87.5	
Strabismus near ( $n=133$ )												
Esotropia (13% $n=18$ )	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% $n=24$ )	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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## REFERENCES

- Adams, G.G., McBain, H., MacKenzie, K., Hancox, J., Ezra, D.G. & Newman, S.P. (2016) Is strabismus the only problem? Psychological issues surrounding strabismus surgery. *Journal of AAPOS*, 20, 383–386. Available from: <https://doi.org/10.1016/j.jaapos.2016.07.221>
- Buffenn, A.N. (2021) The impact of strabismus on psychosocial health and quality of life: a systematic review. *Survey of Ophthalmology*, 66, 1051–1064. Available from: <https://doi.org/10.1016/j.survo.2021.03.005>
- Chang, M.Y., Velez, F.G., Demer, J.L., Isenberg, S.J., Coleman, A.L. & Pineles, S.L. (2015) Quality of life in adults with strabismus. *American Journal of Ophthalmology*, 159, 539–544.e2. Available from: <https://doi.org/10.1016/j.ajo.2014.12.003>
- Durnian, J.M., Noonan, C.P. & Marsh, I.B. (2011) The psychosocial effects of adult strabismus: a review. *The British Journal of Ophthalmology*, 95, 450–453. Available from: <https://doi.org/10.1136/bjo.2010.188425>
- Durnian, J.M., Owen, M.E., Baddon, A.C., Noonan, C.P. & Marsh, I.B. (2010) The psychosocial effects of strabismus: effect of patient demographics on the AS-20 score. *Journal of AAPOS*, 14, 469–471. Available from: <https://doi.org/10.1016/j.jaapos.2010.08.013>
- Flodin, S., Pansell, T., Rydberg, A. & Andersson Grönlund, M. (2020) Clinical measurements of normative subjective cyclotorsion and cyclofusion in a healthy adult population. *Acta Ophthalmologica*, 98, 177–181. Available from: <https://doi.org/10.1111/aos.14201>
- Flodin, S., Rydberg, A., Pansell, T. & Grönlund, M.A. (2021) Measuring health-related quality of life in individuals with cyclodeviation using the adult strabismus 20 (AS-20) questionnaire. *Journal of AAPOS*, 25, 20.e1–20.e6. Available from: <https://doi.org/10.1016/j.jaapos.2020.08.011>
- Georgievski, Z., Sleep, M. & Koklanis, K. (2007) Simulated torsional disparity disrupts horizontal fusion and stereopsis. *Journal of AAPOS*, 11, 120–124.
- Hair, J.F., Tatham, R.L., Anderson, R.E. & Black, W. (1998) *Multivariate Data Analysis*, 5th edition. Upper Saddle River: Prentice Hall.
- Hashemi, H., Pakzad, R., Heydari, S., Yekta, A., Aghamirsalim, M., Shokrollahzadeh, F. et al. (2019) Global and regional prevalence of strabismus: a comprehensive systematic review and meta-analysis. *Strabismus*, 27, 54–65. Available from: <https://doi.org/10.1080/09273972.2019.1604773>
- Hatt, S.R., Leske, D.A., Bradley, E.A., Cole, S.R. & Holmes, J.M. (2009a) Development of a quality-of-life questionnaire for adults with strabismus. *Ophthalmology (Rochester, Minn)*, 116, 139–144.e5. Available from: <https://doi.org/10.1016/j.ophtha.2008.08.043>
- Hatt, S.R., Leske, D.A., Bradley, E.A., Cole, S.R. & Holmes, J.M. (2009b) Comparison of quality-of-life instruments in adults with strabismus. *American Journal of Ophthalmology*, 148, 558–562. Available from: <https://doi.org/10.1016/j.ajo.2009.05.009>
- Hatt, S.R., Leske, D.A. & Holmes, J.M. (2010) Responsiveness of health-related quality-of-life questionnaires in adults undergoing strabismus surgery. *Ophthalmology*, 117, 2322–2328.e1. Available from: <https://doi.org/10.1016/j.ophtha.2010.03.042>
- Hatt, S.R., Leske, D.A., Kirgis, P.A., Bradley, E.A. & Holmes, J.M. (2007) The effects of strabismus on quality of life in adults. *American Journal of Ophthalmology*, 144, 643–647. Available from: <https://doi.org/10.1016/j.ajo.2007.06.032>
- Hatt, S.R., Leske, D.A., Liebermann, L. & Holmes, J.M. (2012) Changes in health-related quality of life 1 year following strabismus surgery. *American Journal of Ophthalmology*, 153, 614–619. Available from: <https://doi.org/10.1016/j.ajo.2011.10.001>
- Hatt, S.R., Leske, D.A., Philbrick, K.L. & Holmes, J.M. (2018) Factors associated with failure of Adult Strabismus-20 Questionnaire scores to improve following strabismus surgery. *JAMA Ophthalmology*, 136, 46–52. Available from: <https://doi.org/10.1001/jamaophthalmol.2017.5088>
- Holmes, J.M., Leske, D.A. & Kupersmith, M.J. (2005) New methods for quantifying diplopia. *Ophthalmology*, 112, 2035–2039. Available from: <https://doi.org/10.1016/j.ophtha.2005.06.013>
- Lavallee, D.C., Chenok, K.E., Love, R.M., Petersen, C., Holve, E., Segal, C.D. et al. (2016) Incorporating patient-reported outcomes into health care to engage patients and enhance care. *Health Affairs (Millwood)*, 35, 575–582. Available from: <https://doi.org/10.1377/hlthaff.2015.1362>
- Leske, D.A., Hatt, S.R., Liebermann, L. & Holmes, J.M. (2012) Evaluation of the Adult Strabismus-20 (AS-20) Questionnaire using Rasch analysis. *Investigative Ophthalmology & Visual Science*, 53, 2630–2639. Available from: <https://doi.org/10.1167/iov.11-8308>
- Leske, D.A., Hatt, S.R., Liebermann, L. & Holmes, J.M. (2016) Lookup tables versus stacked Rasch analysis in comparing pre- and postintervention adult Strabismus-20 data. *Translational Vision Science & Technology*, 5, 11.
- Marsh, I.B. (2015) We need to pay heed to the psychosocial aspects of strabismus. *Eye (London, England)*, 29, 238–240. Available from: <https://doi.org/10.1038/eye.2014.283>
- Mason, A., Joronen, K., Lindberg, L., Koivisto, A.M., Fagerholm, N. & Rantanen, A. (2023) Health-related quality of life in adult patients with strabismus—translation and psychometric testing of the Adult Strabismus Questionnaire (AS-20) into Finnish. *International Journal of Environmental Research and Public Health*, 20, 2830. Available from: <https://doi.org/10.3390/ijerp2023042830>
- McBain, H.B., Au, C.K., Hancox, J., MacKenzie, K.A., Ezra, D.G., Adams, G.G. et al. (2014) The impact of strabismus on quality of life in adults with and without diplopia: a systematic review. *Survey of Ophthalmology*, 259, 185–191. Available from: <https://doi.org/10.1016/j.survophthal.2013.04.001>
- McBain, H.B., MacKenzie, K.A., Au, C., Hancox, J., Ezra, D.G., Adams, G.G. et al. (2014) Factors associated with quality of life and mood in adults with strabismus. *The British Journal of Ophthalmology*, 98, 550–555. Available from: <https://doi.org/10.1136/bjophthalmol-2013-304220>
- McBain, H.B., MacKenzie, K.A., Hancox, J., Ezra, D.G., Adams, G.G. & Newman, S.P. (2016) Does strabismus surgery improve quality and mood, and what factors influence this? *Eye*, 30, 656–667. Available from: <https://doi.org/10.1038/eye.2016.70>
- Munro, B.H. (2005) *Statistical methods for health care research*, 5th edition. Philadelphia: Lippincott Williams & Wilkins.
- Paduca, A., Arnaut, O., Lundmark, P.O. & Bruenech, J.R. (2021) Causes of concomitant strabismus surgery delay in teenagers and adults. *Strabismus*, 29, 151–157. Available from: <https://doi.org/10.1080/09273972.2021.1948070>
- Sah, S.P., Sharma, I.P., Chaudhry, M. & Saikia, M. (2017) Health-related quality of life (HRQoL) in young adults with strabismus in India. *Journal of Clinical and Diagnostic Research*, 11, NC01-NC04. Available from: <https://doi.org/10.7860/JCDR/2017/24541.9389>
- Wang, Z., Zhou, J., Xu, Y., Yin, H., She, X., Bian, W. et al. (2018) Development of a conceptual model regarding quality of life in Chinese adult patients with strabismus: a mixed method. *Health and Quality of Life Outcomes*, 16, 171. Available from: <https://doi.org/10.1186/s12955-018-0991-y>
- Wang, Z.H., Bian, W., Ren, H., Frey, R., Tang, L.F. & Wang, X.Y. (2013) Development and application of the Chinese version of the Adult Strabismus Quality of Life Questionnaire (AS-20): a cross-sectional study. *Health and Quality of Life Outcomes*, 11, 180. Available from: <https://doi.org/10.1186/1477-7525-11-180>

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# PUBLICATION III

**Strabismic adults' experiences of psychosocial influence of strabismus – A qualitative study.**

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# Strabismic Adults' Experiences of Psychosocial Influence of Strabismus—A Qualitative Study

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## Abstract

**Introduction:** Strabismus influences health-related quality of life. Individuals may have functional and psychosocial consequences of strabismus that impact their well-being. As strabismus is prevalent in all age groups, patients are seen in varied specialties in healthcare organizations. Therefore, healthcare professionals need to be aware of the psychosocial consequences when caring for strabismic individuals.

**Objective:** To describe strabismic adults' experiences of the psychosocial influence of strabismus.

**Methods:** Twelve strabismic adults participated in face-to-face or online semistructured individual interviews to share their experiences of the psychosocial influence of strabismus. The participants were selected purposefully. The data were analyzed using inductive content analysis.

**Results:** The participating adults described challenges with social environments, which showed stress in social situations and pressure in interactions. Strabismic adults had experienced staring from others, avoided social situations, and were uncomfortable with photography. They hid their strabismus, avoided eye contact, and struggled with intimate relationships. They also expressed struggles with mental well-being, which were emotional and psychological burdens. The adults described feeling negative emotions, worry, and irritation due to their condition. Struggles with self-confidence, difficulties with acceptance, negative thoughts about their appearance, experiences of bullying, and dealing with being different were described.

**Conclusion:** Strabismic adults experience psychosocial consequences of strabismus, influencing their psychosocial health-related quality of life. Further studies should focus on how healthcare professionals could support strabismic individuals' psychosocial well-being.

## Keywords

strabismus, psychosocial health-related quality of life, psychosocial well-being, nursing, qualitative research, inductive content analysis

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## Introduction

Strabismus is an eye condition whereby the eyes are misaligned; it is most often visible as one eye points in a different direction. The strabismic eye might turn in any direction or rarely rotate around its axis. The eye can be constantly or intermittently deviated, or the condition can alternate between the eyes. Worldwide, 3%–4% of adults have strabismus (Buffenn, 2021; Fieß et al., 2020; Hashemi et al., 2019; MacKenzie et al., 2016). Adults might have childhood-onset strabismus, or strabismus might be secondary to other conditions, such as thyroid eye disease, trauma, cranial nerve palsies, neurological diseases, or vision

loss (Al-Omari et al., 2022). Surgical and nonsurgical treatments, such as glasses and prism lenses, are used to treat strabismus (Buffenn, 2021; MacKenzie et al., 2016).

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Health-related quality of life (HRQOL) can be defined as one's well-being and functioning in the physical, mental, and social dimensions of life (Kaplan & Hays, 2022). Strabismus can influence all these dimensions. Blurred or double vision (diplopia), ocular discomforts, tiredness of the eyes, and abnormal head or body posture can affect physical function. The symptoms disrupt everyday life: watching TV, reading, cooking, and partaking in hobbies; driving may also be difficult (Kumaran et al., 2019; Wang et al., 2018). Strabismus can also influence interpersonal relationships, making one hide their strabismic eye and avoid social interactions. As the condition changes one's facial appearance, it can affect self-image, and bullying decreases mental and social well-being. People with strabismus may have symptoms of depression, negative emotions, and anxiety and struggle with self-perception and appearance-related issues (Ehlers et al., 2023; MacKenzie et al., 2016; Paduca et al., 2021; Wang et al., 2018). Due to the visibility of strabismus, employers might have misconceptions about persons living with strabismus, and the chance to obtain employment or promotion may be reduced, thus impacting one's economic well-being. Additionally, lower visual functioning is a risk for injuries; therefore, strabismus can be considered a public health concern (Buffenn, 2021; Wang et al., 2018).

## Review of the Literature

The Adult Strabismus Questionnaire (AS-20) can assess strabismic adults' HRQOL. The AS-20 was developed by interviewing patients about their experiences living with strabismus (Hatt et al., 2009). The Finnish version of AS-20 is available for Finnish patients (Mason et al., 2023). Health-related quality of life is lower in strabismic compared to nonstrabismic adults, and strabismic women have lower overall and psychosocial HRQOL than strabismic men (Al-Omari et al., 2022).

Strabismus surgery generally increases one's HRQOL concerning physical and psychosocial well-being. Anxiety and depression levels have improved postoperatively (Ehlers et al., 2023). However, clinically successful surgery does not always improve psychosocial well-being; for some patients, preoperative psychosocial support could be helpful (MacKenzie et al., 2016). Individuals commonly seek surgery to improve their appearance, increase self-confidence, enhance social relationships, and receive better job opportunities (Al-Omari et al., 2022; Paduca et al., 2021). Often, patients with strabismus and surgery in childhood will require treatment in adulthood as the condition can reoccur (Al-Omari et al., 2022).

Nurses have an overarching role in the multidisciplinary team, providing care for patients in varied sectors of healthcare organizations (Lindahl Norberg & Strand, 2022). As people living with strabismus might present to nurse clinics in occupational, student health, or even a variety of specialties in hospitals, nurses should be aware and educated on how strabismus influences one's HRQOL, particularly in the psychosocial dimension, to improve care for all patients (Buffenn, 2021).

Previous international studies show that strabismus has psychosocial implications on HRQOL (Al-Omari et al., 2022; Ehlers et al., 2023; Wang et al., 2018). To further understand the consequences of strabismus, a qualitative study aiming to describe strabismic adults' experiences of the psychosocial influence of strabismus was conducted.

## Methods

### Design

This study has a qualitative descriptive design, using semistructured interviews and inductive content analysis. A qualitative method was selected to explore and understand phenomena within this population (Holloway & Galvin, 2017; Kyngäs, 2019b). The COREQ checklist guided the reporting of the study.

### Participants and Setting

This study was conducted at a university hospital's ophthalmology outpatient clinic specializing in strabismus. The clinic cares for strabismic adults and children; in 2022, over 3000 outpatient visits and approximately 350 surgeries occurred.

Participants were recruited purposefully to reach the most informative participants who would share their experiences for the study (Moser & Korstjens, 2018). The study initially aimed to describe the experiences of the psychosocial influence of strabismus and then describe the patients' expectations for psychosocial support. This article reports the experiences of the psychosocial influence of strabismus. Inclusion criteria were adult patients ( $\geq 18$  years) attending the clinic with experiences of the psychosocial influence of strabismus. They had to be able to communicate in Finnish and have no severe psychiatric or neurological illnesses. Multiprofessional staff at the unit approached patients who had answered *sometimes, often, or always* on the Finnish AS-20 items 1–10 measuring psychosocial HRQOL (Mason et al., 2023) and offered to participate in this study. Participation was voluntary and did not affect care.

Altogether, 18 patients with visible strabismus were approached, of which 13 volunteered, received a written information leaflet, and signed a consent form. Five declined to participate due to their schedules or lack of interest. One did not reply to requests for an interview despite several attempts to contact them. Therefore, 12 adult patients were interviewed. Patients could choose whether to participate in an individual face-to-face or online interview. Eight interviews were held face-to-face at the clinic after the patient's appointment and four online on Microsoft Teams™ at a suitable time for the patients. With participants' permission, the interviews were audio-recorded; three online interviews were video-recorded.

### Data Collection

The data were collected between August 2022 and February 2023 using a semistructured interview guide. The first author

(AM) is a doctoral researcher in nursing science and conducted interviews independently as a full-time researcher. The interview guide was produced jointly with the research group. Neither the first author nor the research group knew the interviewees.

All the interviews commenced with the first author explaining the research objective, data security, confidentiality, and the previous and next steps of the PhD study. The first author ensured participation was voluntary and that the participants approved the recording. It was explained that the interviewer had a nursing background but was not a clinical expert on strabismus and did not participate in the clinical care of strabismic patients. However, due to their years of working in ophthalmology, the interviewer had developed an interest in studying the influence of strabismus on Finnish adults' HRQOL. How the study's results could be used to further improve the services for strabismic patients was also explained.

Background questions included sex and age, which were categorized to maintain anonymity. The questions regarding strabismus concerned whether strabismus was in one or both eye(s), the onset of strabismus, and previous strabismus surgeries. Patients were asked to describe their experiences of how strabismus influenced their social well-being, such as interactions and social relationships and situations. Exploratory questions such as *you mentioned earlier... can you please tell me more... I understood you saying... did I understand that correctly... is there anything else you would like to tell me on this subject...* were used to deepen the knowledge of the experiences as guided by Holloway and Galvin (2017). Following the open-ended question on social well-being, the influence of strabismus on psychological well-being, such as mental well-being, feelings, and thoughts of self, was inquired. The same exploratory questions were used. All adults were interviewed once; the interviews lasted from 28 to 45 min. Field notes were written during the interviews. Data saturation—a point in data collection when no more new experiences were described—was achieved after ten interviews (Kyngäs, 2019b; Moser & Korstjens, 2018). However, two more interviews were conducted to ensure the data answered the research questions.

### Data Analysis

The data were analyzed using the inductive content analysis approach to gain a deeper understanding of the phenomenon, as the previous knowledge is deficient (Kyngäs, 2019a). The recordings were transcribed verbatim, and the transcriptions were checked by listening to the recordings. The transcriptions comprised 83 pages of text, including the following research questions: (1) How has strabismus affected your psychosocial well-being? and (2) What kind of psychosocial support do you expect from healthcare professionals? The second research question is reported in a separate article. The first author read the transcriptions several times to gain an understanding of the participants' experiences. With the research objective clearly in

focus, meaning units were chosen from the transcribed text to describe the strabismic adults' experiences. Field notes and an interview diary strengthened the interpretations. Meaning units were condensed and then grouped to form subcategories of similar experiences. Several meaning units had more than one condensed meaning unit. Subcategories were given descriptive names and further connected to form categories. The research group discussed and reviewed the analysis at all stages (Kyngäs, 2019a). The meaning units were translated into English to report the results. Table 1 presents an example of the analysis.

### Ethical Considerations

The Declaration of Helsinki was followed (WMA, 2013). Ethical and organizational approvals were acquired from the healthcare organization. Participants were given verbal and written information about the study before signing the consent form. Participation was voluntary. Patients were told they could stop their participation at any time; however, the information they share can be used in the study as per ethical and research permissions (Holloway & Galvin, 2017). Individuals were also informed they have a right to an appointment with a psychologist if they feel they need it.

For patient confidentiality, face-to-face individual interviews were held in hospital rooms with soundproof doors, and online meetings were arranged so no one else was in the interviewer's room. Individuals were told that their names had been replaced in the study with ID codes, and only the first author had access to the files connecting ID codes and names. All data were saved in the first author's hospital's secure database, following the organization's data policy. Recordings were deleted after being transcribed and checked. The research team discussed the findings to fully understand the phenomenon, and the first author returned to the transcriptions several times to confirm the participants' experiences (Holloway & Galvin, 2017).

## Results

### Participant Characteristics

The participants ( $n = 12$ ) were eight females and four males who sought care for strabismus. Most had childhood-onset strabismus ( $n = 9$ ) and at least one previous surgery ( $n = 9$ ). Table 2 reports the participants' characteristics.

The strabismic adults shared their experiences with strabismus; these experiences created challenges with their social environment and added to their mental health struggles. Results are presented in Figure 1 and described with the authentic quotations.

### Challenges with the Social Environments

*Stress in Social Situations.* Participants described having unpleasant experiences in social situations where people

**Table 1.** Example of the Analytical Process.

Meaning unit	Condensed meaning unit	Subcategory	Category	Main category
"I really hate to be photographed because strabismus can always be seen in the photos... that's why I avoid those situations." ID 12	Hates to be photographed, as strabismus shows in the photos ID 12	Discomfort with being photographed	Stress in social situations	Challenges with the social environment
"If there have been any photography sessions, I went...but I have always felt that I don't want to go anywhere where photos are taken." ID 13	Does not want to go anywhere where photos are taken ID 13			
"With strangers... as in public places, people have more courage there, even to stare, compared to this room, as the situation is different, and people are not brave to stare here." ID 20	Strangers are braver about staring in public places ID 20	Experiences of people staring		
"People stare... it is impossible not to notice." ID 2	Staring from others is noticed ID 2			
"For sure, it is difficult for me to look people in the eye; I try to avoid it so the other would not notice my eye." ID 19	Tries to avoid eye contact so others would not notice the eye ID 19	Avoiding eye contact	Pressure in interactions	
"I haven't had the time to get used to it (strabismus), and I always avoid all eye contact." ID 4	Always avoids all eye contact ID 4			
"And then... I am constantly fixing my eye. I blink and move my gaze—like I know when I look at you, my eye is playing its own game." ID 20	Blinking so strabismus does not show ID 20	Hiding strabismus		
"When I look at myself on the computer screen and see my strabismus, I start to avoid... I might not look straight ahead or in the eye, but I try to look from an angle so that the strabismus would not show... It is not a pleasant situation." ID 3	Tries to look from an angle to hide strabismus ID 3			

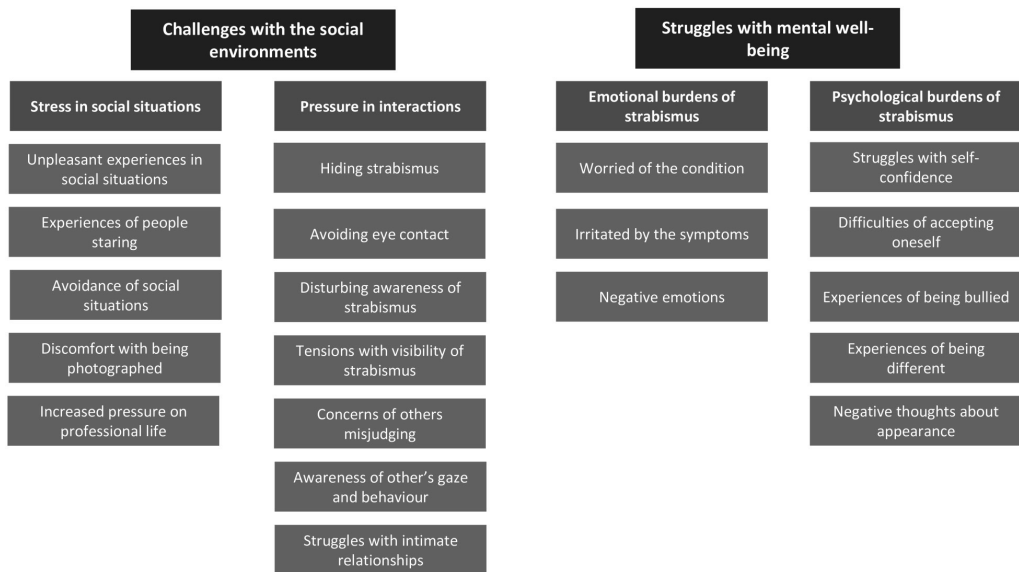
**Table 2.** Participants' Characteristics.

Participant ID	Sex	Age categorized	Previous surgery	Onset of strabismus	Interview method	Duration (in minutes)
1	Female	18–30	1	Childhood	Online	35
2	Female	64–	0	Adult	Face-to-face	44
3	Male	45–63	3	Childhood	Online	40
4	Female	64–	1	Adult	Face-to-face	38
8	Female	45–63	1	Childhood	Face-to-face	34
9	Male	31–44	1	Childhood	Face-to-face	28
10	Male	45–63	0	Adult	Face-to-face	34
11	Male	18–30	2	Childhood	Face-to-face	36
12	Female	18–30	2	Childhood	Online	36
13	Female	18–30	3	Childhood	Face-to-face	35
19	Female	31–44	2	Childhood	Online	45
20	Female	18–30	1	Childhood	Face-to-face	44

had looked past them or avoided looking at them. Situations when someone had asked about or commented on their eyes made them feel bad. Being in crowded places, such as on a bus, was stressful as people could easily notice their strabismus.

"Well, it is probably that... others do not look straight into my eye but avoid it altogether." ID 9

They recounted experiences of people staring at them. They felt others were very interested in their eyes and



**Figure 1.** Experiences of psychosocial influence of strabismus.

generally tried to stare discreetly but failed. They also suggested that people stare because they do not know about the condition.

“Some people stare for long and don’t seem to be able to stop staring; it makes me so uncomfortable.” ID 20

Individuals avoided social situations due to their eyes, stating that staying home rather than facing the reactions of strangers was easier for avoiding misunderstandings. With strabismus, the eye can look like it is pointing in a different direction than where the strabismic person is looking, which can create misinterpretation or even conflict in social situations.

“I don’t go to all places because I am worried there will be a misunderstanding, as my eye points somewhere else, which causes me stress.” ID 11

Being photographed was uncomfortable. Participants recounted childhood and adolescent experiences from school photography sessions and how uncomfortable they had felt as strabismus showed easily in the photos. Recently, they felt challenged by friends continuously updating their social media with selfies.

“All the school photos—I did not like them at all. I had to think about hiding the strabismus by keeping my head bit sideways... but it was there... always, everyone will

remember me like this. It was stressful; I don’t think many with strabismus like having photos taken.” ID 13

Strabismus negatively influenced professional life. Participants described their experiences of work- or study-related presentations when they had the expertise and knowledge to speak, but pondering the visibility of strabismus made the situation awkward and stressful. Individuals working in customer service expressed that strabismus had sometimes caused conflicts with customers, as the customers felt the agent was not looking at them but past them.

“In giving presentations at work, I feel awkward as I have to constantly think about whether my strabismus is showing.” ID 3

**Pressure in Interactions.** Patients described avoiding eye contact in interactions, as they were aware of strabismus and did not want to cause confusion. Symptoms of strabismus, such as diplopia, also made maintaining eye contact difficult. They hoped that after corrective surgery, they could look people straight in the eye. They explained that if the person they interact with knows the situation, they try to maintain eye contact.

“Now, when I know what this situation—this interview—is all about, I can look this way straight at you... But when I don’t know, I avoid eye contact, so the condition does not show.” ID 2

The patients explained hiding their strabismus so others would not see it. Practical examples included scratching, rubbing, blinking, or closing the strabismic eye, looking down or somewhere else, standing a particular way, tilting their head, looking sideways, and always turning their whole body rather than just their head. Some planned their seating at social gatherings in a way so they would not be opposite strangers. They expressed that although hiding is mostly an automatic act, it takes energy in interactions.

“When I speak in a big group, well, I can’t turn my gaze towards the person because I get a feeling... because then the person I am speaking to sees my strabismus... So I have to turn my whole body towards the person so they cannot see it.” ID 1

Strabismus could be felt continuously; thus, it was constantly in their thoughts throughout the day. It could not be forgotten or ignored as it bothered the participants, thus impacting interactions.

“This is so visible... It is present all the time... I can’t forget it and ignore it... Everybody sees it, and I can feel it constantly.” ID 4

Interviewees thought of the visibility of their strabismus often and expressed that it might create tension in interactions, making them seem more reserved and unlike themselves when connecting with people. During interactions, particularly when meeting new people, they expressed wondering greatly if the other person noticed their strabismus, what they thought of their eyes, how they reacted to their eyes, or whether they felt tension during the interaction. They also felt that discussing strabismus with new people was difficult; if they did mention it, their new acquaintances would notice their condition.

“Well, it is always on my mind, and I think of what the other person thinks of me when my eyes are like this.” ID 13

Interviewees described feelings of others misjudging them and thinking of them as weird, stupid, or unintelligent because of their eyes. They felt that people judged them and looked down on them as if strabismus made them unequal.

“Sometimes, I feel that during an interaction, the other person thinks I am weird because of my eye and looks down on me—like I am not equal to them. Yes, this is my feeling, but their body language reveals this, and their facial expressions do, too.” ID 11

Participants explained that they read other people’s behavior and focused on their eyes to assess where the other is looking, as they did not want their strabismus to make the

other person uncomfortable. However, they saw how people looked at their eyes and quickly realized how the other person’s behavior changed when the condition was noticed.

“I am aware... in the interaction, I follow the other’s eyes closely... particularly because they are looking at me... These are the things I am aware of, but I feel that others do not really understand.” ID 12

Strabismus was considered a struggle in intimate relationships. Finding a life partner was more difficult, as potential partners might fear the condition. First dates caused additional pressure, as the participants wondered if their strabismus should be mentioned before the date or if the date noticed their condition from the photo. Some felt their partner was sometimes ashamed of their appearance and feared their eyes had been why their previous relationships had not flourished.

“Well, yes, it is... finding a partner has been challenging.. Well, hmm, maybe they fear the other one looks so different—in appearance, I mean.” ID 9

### *Struggles with Mental Well-Being*

*Emotional Burdens of Strabismus.* The patients feared their strabismus worsening or not knowing why their eye had deteriorated. Availability and accessibility of the treatment options caused concerns, and they recalled feeling occasional anxiety about their eyes.

“So, the kind of worry I have... can strabismus get even worse than it is now... or can I receive help... and is there even help for my eyes... or do I have to manage with just one eye?” ID 10

Strabismus symptoms irritated the participants. They described difficulties with eye fatigue, the inability to work long periods on the computer, and the need for several different glasses for different situations.

“Sometimes, it is so annoying... with those glasses... I have ten different pairs of glasses and must think about what I shall wear now... oh, I can’t watch TV now—now I have to cover my eye... it is a hassle.” ID 4

Having strabismus provoked negative emotions such as feeling upset, embarrassed, shame, and psychological pain. Feeling upset was occasional, particularly when they were alone or reliving memories from adolescence when strabismus had caused them to feel bad about themselves. Depressive thoughts and anxiety were infrequent and undiagnosed. Embarrassment and shame were connected to social situations with others and the inability to work in the profession they trained for.

“Being off work is so embarrassing and shameful... I can’t work due to the symptoms of strabismus, and I feel embarrassment and shame because of it.” ID 8

**Psychological Burdens of Strabismus.** Participants struggled with self-confidence. They mentioned feeling inadequate, particularly in puberty, to others with nonstrabismic eyes. Self-confidence was not developed during adolescence due to misalignment, impacting their choices for further education. Lack of self-confidence in adolescence caused self-criticism and sometimes manifested as self-disruptive behavior. Self-confidence was also influenced by the lack of the general public’s understanding of strabismus, as adults living with strabismus felt they had to prove themselves more than others without the condition.

“Yes, I feel that strabismus has impacted my studying... probably mostly due to self-confidence, which I feel has not developed as it should have. So, I have many issues... I was interested in studying a particular field. I would have loved to go to the university and get a degree, but I feel I am not enough for this or that.” ID 19

Acceptance of oneself with misaligned eyes was reported as an ongoing process that is not yet complete. Participants mentioned living with poor eyesight was preferable than coping with strabismus and that life would be better if their eyes were straightened. As strabismus cannot always be corrected by surgery or other treatments, acceptance felt very difficult.

“Well, I have to all the time... continuously work in my mind that I am good and am okay with the way I am. It does not matter... I feel that sometimes I have managed this well, but it is such hard work... so hard.” ID 13

The interviewees had experienced bullying, mostly in childhood and in adulthood. They were called ugly names—weird, stupid, and stupid-looking—mostly at school. In adulthood, they had received comments from dating apps or others in interactions. Bullying had crushed their self-confidence, causing upset, and further psychological implications.

“But, yes. Once I received feedback. Someone I know said this to me.. Yuck! Why are your eyes like that?...No one will ever want you... and then I really collapsed and cried every day.” ID 1

They also described feeling different from others; for example, in childhood, they were the only ones with misaligned eyes in their year. Now, as adults, they were the only ones with strabismus in their social and professional circles. As they could not look straight, they were different. They described their first time at the clinic as surprisingly positive, as they had seen others with the same condition.

“I had not met anyone who also had strabismus... so I had thought that because I am the only one with strabismus in my hometown, I am different. And then I came here and saw others with strabismus and realized I am not the only one... it felt good.” ID 2

Strabismic adults thought negatively about their appearance and expressed that their eyes made them look less attractive. Younger or female participants mentioned this in particular. Others had told them not to worry about their eyes and appearance but as appearance mattered to them, not worrying was impossible.

“I always talk about my eye—that it is crossed. I suffer so much from it... For me appearance has always been important... therefore, I am so bothered by this crooked eye.” ID 4

## Discussion

This study aimed to describe strabismic adults’ experiences of the psychosocial influence of strabismus. As the phenomenon is not widely studied, qualitative research with semi-structured interviews was conducted.

Participants recalled stress in social situations, such as unpleasant experiences and people staring, causing them to avoid social gatherings and interactions. They also described how uncomfortable they found being photographed and wanted to avoid those situations, as strabismus is visible in photos. These results strengthen Wang et al.’s (2018) previous findings. The adults expressed avoiding eye contact and hiding their strabismus to prevent others from seeing their eyes, which could be due to previous unpleasant experiences in social situations, as MacKenzie et al. (2016) indicated. Asymmetry of the eyes could also be interpreted as unfriendliness or impoliteness (Wang et al., 2018), which could explain why the participants of the current study avoided eye contact and social situations and hid their strabismic eye. The interviewees expressed concerns about others misjudging them and thinking of them as being less intelligent. Estes et al. (2020) discuss public self-consciousness and one’s belief in how others perceive them. Their research shows that strabismus surgery improves patients’ public self-consciousness and reduces social anxiety. This indicates that people living with strabismus suffer from what others might think of them, which may generate social anxiety (Estes et al., 2020). The current study participants described struggles in intimate relationships due to their eyes, aligning with Wang et al.’s (2018) previous study and the reasons for strabismic adults’ seeking surgical treatment as Paduca et al. (2021) and Al-Omari et al. (2022) reported.

Strabismus emotionally burdened the patients who described fearing their condition worsening or treatment being unavailable. Education of healthcare personnel and

increased general awareness of strabismus can relieve these concerns. Previous research states that adults can delay seeking help due to many misconceptions about strabismus, and correct education can reduce these misconceptions and the delay in accessing services (Al-Omari et al., 2022; Paduca et al., 2021; Wang et al., 2018).

Negative emotions were common, as Wang et al. (2018) reported previously. The strabismic adults described feeling upset about the situation and occasionally felt depressive feelings and anxiety. However, these occasional feelings were not assessed on a measure, such as the Hospital Anxiety and Depression Scale, which Ehlers et al. (2023) used for their study. In the current study, as by Wang et al. (2018), the interviewees also expressed embarrassment, shame of their eyes and the situation.

Strabismus affects adults' self-confidence in many ways. This aligns with Paduca et al.'s (2021) study, where improved self-confidence was one motivator for young adults and adults to seek surgical treatment. Many recounted experiences of bullying in the current study. Although most of the experiences were in childhood, a few had been exposed to mean comments as adults. Bullying had caused psychological implications, concurring with previous studies (Buffenn, 2021; Wang et al., 2018). Most childhood-onset strabismus develops before age 10, and the difference in appearance can cause negative attitudes and social bias from others (Huang & Pineles, 2023). As adults recounted bullying at schools, school staff should be aware of bullying due to strabismus, and education on strabismus should be provided for the staff and pupils.

Participants expressed negative thoughts on their appearance, as they felt they were unattractive. Wang et al.'s (2018) study also described these experiences, although the cultural context differs. Strabismus alters appearance by changing the symmetry of the eyes (Buffenn, 2021; Wang et al., 2018). Therefore, providing surgical treatment for strabismic adults can reconcile patients' appearance to match society's expectations of normal (Estes et al., 2020), easing the feelings of being different and diminishing the negative thoughts about their appearance. However, for some strabismic adults, surgery does not improve psychosocial well-being (MacKenzie et al., 2016); thus, preoperative psychosocial support is needed (Ehlers et al., 2023).

### Strengths and Limitations

Criteria of trustworthiness in a qualitative study are defined as credibility, transferability, dependability, and confirmability (Korstjens & Moser, 2018). This study was conducted by interviewing patients who had experienced psychosocial hindrances of strabismus and were willing and able to share their subjective experiences. Inclusion criteria and purposeful recruitment enabled identifying and approaching persons with experience on the psychosocial influence of strabismus. A doctoral researcher with previous interviewing experience

conducted the interviews. The participants are described, and their authentic quotations are used in the results, enhancing the study's credibility and transferability. Dependability is supported by describing details of data collection and analysis. Additionally, confirmability is improved by constant reflection, self-awareness, and discussions throughout the process with the research team (Korstjens & Moser, 2018). These strengthen the study.

The results are experiences of 12 strabismic individuals, and they are not generalizable to all people living with strabismus. This is a common limitation of qualitative studies. However, increasing awareness of the psychosocial influence of strabismus to improve patient-centered care is important. It is worth noting that dependability would have been increased by involving participants in evaluating findings, which was impossible in this study (Korstjens & Moser, 2018). Transferability to other strabismic patients would have been improved even further by reporting participants' AS-20 scores and the clinical data, such as diplopia and the direction and amount of strabismus. Future studies need to observe this.

### Implications for Practice

This study's results can be used to educate healthcare professionals on the psychosocial consequences of strabismus and provide support for strabismic patients of all ages. Support for psychosocial well-being should be available for people living with strabismus.

### Conclusions

Strabismic adults experience psychosocial influence of strabismus, both with challenges in their social environment and struggles with mental well-being. Stress in social situations, pressure in interactions, and the emotional and psychological burdens of strabismus influence adults' HRQOL. As participating adults reflected many experiences from their childhood and adolescence, it is imperative to understand how strabismus influences psychosocial well-being in children and adolescents and provide timely support for their psychosocial health. Health and social care professionals working in childhood, adolescent, and adult services, including educational environments, should understand the psychosocial challenges of people living with strabismus to support and guide them toward available care. Additionally, these results can increase the general societal awareness of strabismus.

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## Author Contributions

All authors contributed to designing and implementing the research, analyzing and interpreting the results, and reviewing and editing the draft of the manuscript. All authors approved the final submitted version of the manuscript and agreed to the order of the author names.

## Data Availability

Data cannot be shared due to the ethical approval of the study.

## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.


## Ethical Review

This study was approved by the Ethics Committee of the HUS Helsinki University Hospital (HUS/3264/2021), and the research permission was obtained from the HUS Helsinki University Hospital Head and Neck Center (HUS/148/2022).

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## Supplemental Material

Supplemental material for this article is available online.

## References

- Al-Omari, R., Jammal, H. M., Khader, Y., Atoum, D., Al-Dolat, W., & Khatatbeh, M. (2022). Adults with longstanding strabismus: Psychosocial and functional impacts and reasons behind surgery delay. *Journal of Ophthalmology*, 2022, 1–7. <https://doi.org/10.1155/2022/8682675>
- Buffenn, A. N. (2021). The impact of strabismus on psychosocial health and quality of life: A systematic review. *Survey of Ophthalmology*, 66(6), 1051–1064. <https://doi.org/10.1016/j.survophthal.2021.03.005>
- Ehlers, M., Mauschwitz, M. M., & Wabbels, B. (2023). Implementing strabismus-specific psychosocial questionnaires in everyday clinical practice: Mental health and quality of life in the context of strabismus surgery. *BMJ Open Ophthalmology*, 8(1), e001334. <https://doi.org/10.1136/bmjophth-2023-001334>
- Estes, K. J., Parrish, R. K., Sinacore, J., Mumby, P. B., & McDonnell, J. F. (2020). Effects of corrective strabismus surgery on social anxiety and self-consciousness in adults. *Journal of American Association for Pediatric Ophthalmology and Strabismus*, 24(5), 280.e1–280.e4. <https://doi.org/10.1016/j.jaapos.2020.05.017>
- Fieß, A., Elflein, H. M., Urschitz, M. S., Pesudovs, K., Münzel, T., Wild, P. S., Michal, M., Lackner, K. J., Pfeiffer, N., Nickels, S., & Schuster, A. K. (2020). Prevalence of strabismus and its impact on vision-related quality of life: Results from the German population-based Gutenberg Health Study. *Ophthalmology*, 127(8), 1113–1122. <https://doi.org/10.1016/j.ophtha.2020.02.026>
- Hashemi, H., Pakzad, R., Heydari, S., Yekta, A., Aghamirsalim, M., Shokrollahzadeh, F., Khoshhal, F., Pakbin, M., Ramin, S., & Khabazkhoob, M. (2019). Global and regional prevalence of strabismus: A comprehensive systematic review and meta-analysis. *Strabismus*, 27(2), 54–65. <https://doi.org/10.1080/09273972.2019.1604773>
- Hatt, S. R., Leske, D. A., Bradley, E. A., Cole, S. R., & Holmes, J. M. (2009). Development of a quality-of-life questionnaire for adults with strabismus. *Ophthalmology*, 116(1), 139–144.e5. <https://doi.org/10.1016/j.ophtha.2008.08.043>
- Holloway, I., & Galvin, K. (2017). *Qualitative research in nursing and healthcare* (4th ed.). John Wiley & Sons Inc.
- Huang, T. L., & Pineles, S. L. (2023). Strabismus and pediatric psychiatric illness: A literature review. *Children*, 10(4), 607. <https://doi.org/10.3390/children10040607>
- Kaplan, R. M., & Hays, R. D. (2022). Health-related quality of life measurement in public health. *Annual Review of Public Health*, 43(1), 355–373. <https://doi.org/10.1146/annurev-publhealth-052120-012811>
- Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *The European Journal of General Practice*, 24(1), 120–124. <https://doi.org/10.1080/13814788.2017.1375092>
- Kumaran, S. E., Khadka, J., Baker, R., & Pesudovs, K. (2019). Functional limitations recognised by adults with amblyopia and strabismus in daily life: A qualitative exploration. *Ophthalmic and Physiological Optics*, 39(3), 131–140. <https://doi.org/10.1111/opo.12610>
- Kyngäs, H. (2019a). Inductive content analysis. In H. Kyngäs, K. Mikkonen, & M. Kääriäinen (Eds.), *The application of content analysis in nursing science research* (pp. 13–19). Springer International Publishing AG.
- Kyngäs, H. (2019b). Qualitative research and content analysis. In H. Kyngäs, K. Mikkonen, & M. Kääriäinen (Eds.), *The application of content analysis in nursing science research* (pp. 3–11). Springer International Publishing AG.
- Lindahl Norberg, A., & Strand, J. (2022). “We have to be the link between everyone”: A discursive psychology approach to defining registered nurses’ professional identity. *Nursing Open*, 9(1), 222–232. <https://doi.org/10.1002/nop2.1056>
- MacKenzie, K., Hancox, J., McBain, H., Ezra, D. G., Adams, G., & Newman, S. (2016). Psychosocial interventions for improving quality of life outcomes in adults undergoing strabismus surgery. *The Cochrane Database of Systematic Reviews*, 2016(5), CD010092. <https://doi.org/10.1002/14651858.CD010092.pub4>
- Mason, A., Joronen, K., Lindberg, L., Koivisto, A. M., Fagerholm, N., & Rantanen, A. (2023). Health-related quality of life in adult patients with strabismus-translation and psychometric testing of the Adult Strabismus Questionnaire (AS-20) into Finnish. *International Journal of Environmental Research and Public Health*, 20(4), 2830. <https://doi.org/10.3390/ijerph20042830>

- Moser, A., & Korstjens, I. (2018). Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. *The European Journal of General Practice, 24*(1), 9–18. <https://doi.org/10.1080/13814788.2017.1375091>
- Paduca, A., Arnaut, O., Lundmark, P. O., & Bruenech, J. R. (2021). Causes of concomitant strabismus surgery delay in teenagers and adults. *Strabismus, 29*(3), 151–157. <https://doi.org/10.1080/09273972.2021.1948070>
- Wang, Z., Zhou, J., Xu, Y., Yin, H., She, X., Bian, W., & Wang, X. (2018). Development of a conceptual model regarding quality of life in Chinese adult patients with strabismus: A mixed method. *Health & Quality of Life Outcomes, 16*(1), 171. <https://doi.org/10.1186/s12955-018-0991-y>
- WMA (2013). World medical association declaration of Helsinki: Ethical principles for medical research involving human subjects. *JAMA, 310*(20), 2191. <https://doi.org/10.1001/jama.2013.281053>

# PUBLICATION IV

**Strabismic adults' expectations of psychosocial support from healthcare professionals – A qualitative descriptive study.**

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Submitted



