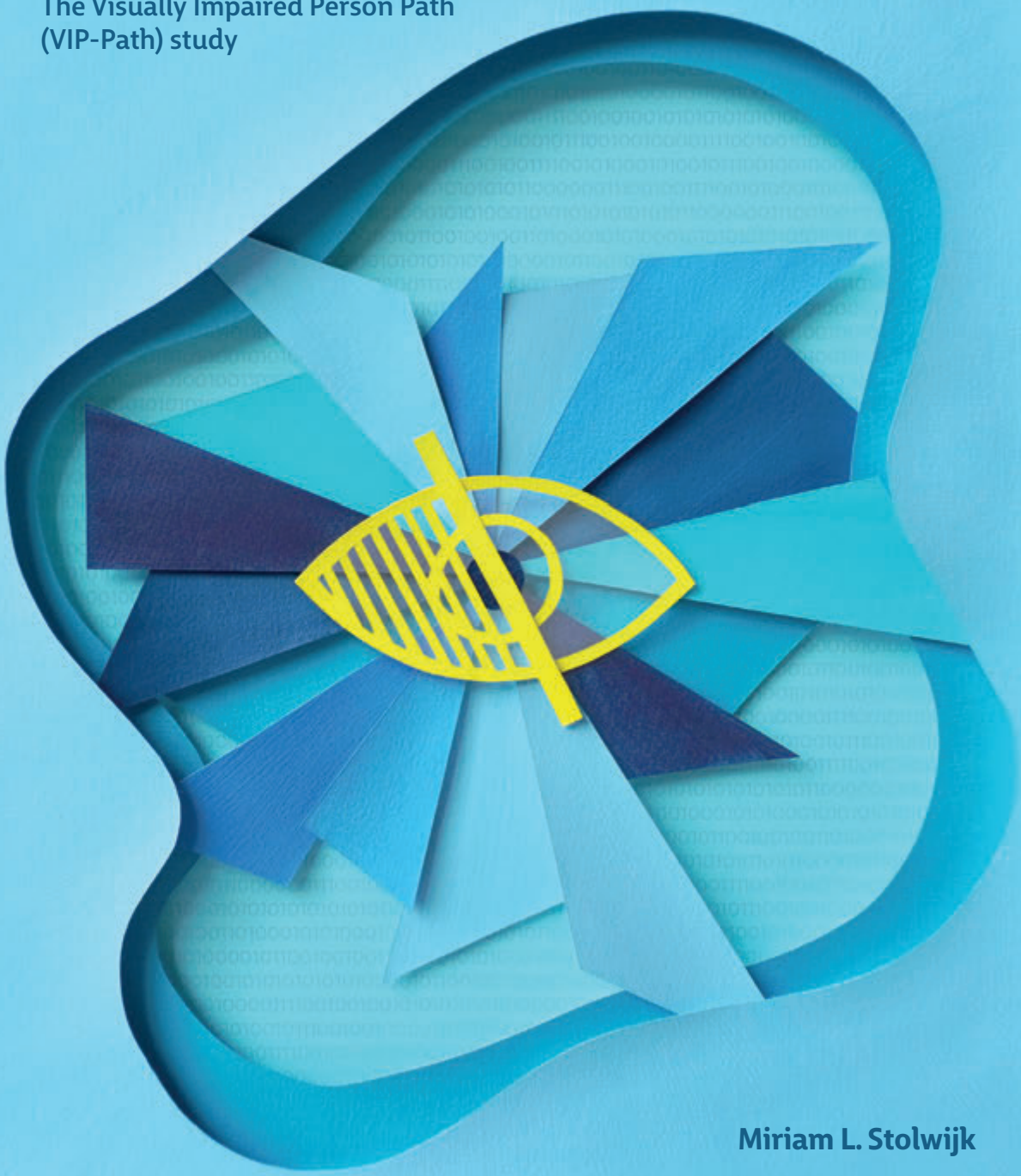
Identifying factors influencing the **referral pathways** towards **low vision services**

The Visually Impaired Person Path (VIP-Path) study



Miriam L. Stolwijk

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The studies presented in this thesis were conducted within the department of Ophthalmology, Amsterdam UMC, Vrije Universiteit Amsterdam and the Amsterdam Public Health research institute, Amsterdam, the Netherlands.

The research presented in this thesis was financially supported by Visio Foundation.

Additional financial support for printing this thesis was kindly provided by Koninklijke Visio, Rotterdamse Stichting Blindenbelangen, Stichting Blindenhulp, Stichting tot verbetering van het Lot der Blinden, and Landelijke Stichting voor Blinden en Slechtzienden.

Cover & Lay-out: Esther Scheide | www.proefschriftomslag.nl
Printing: Ridderprint | www.ridderprint.nl
ISBN: 978-94-6506-696-7
DOI: http://doi.org/10.5463/thesis.846

VRIJE UNIVERSITEIT

Identifying factors influencing the referral pathways towards low vision services

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ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad Doctor of Philosophy aan
de Vrije Universiteit Amsterdam,
op gezag van de rector magnificus
prof.dr. J.J.G. Geurts,
in het openbaar te verdedigen
ten overstaan van de promotiecommissie
van de Faculteit der Geneeskunde
op vrijdag 14 februari 2025 om 13.45 uur
in een bijeenkomst van de universiteit,
De Boelelaan 1105

door

Miriam Laura Stolwijk

geboren te Münster, Duitsland

promotor:	prof.dr. G.H.M.B. van Rens
copromotor:	prof. dr. R.M.A. van Nispen
promotiecommissie:	prof.dr. N. Schrage prof.dr. J.R. Vingerling dr. M. van Hecke prof.dr. S.M. Imhof prof.dr. H. Tan

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CHAPTER 1

General introduction

Low Vision Services (LVS) help people with a visual impairment to improve or gain back their quality of life. However, barriers in LVS referral pathways have been reported, preventing people with visual impairment and potential LVS needs to receive that care. Some may be able to manage themselves or may have sufficient support by their surroundings and may not have LVS needs. Others may be informed and referred late about LVS despite LVS needs. It is still not fully understood why some people receive LVS and some do not. Against this background, this thesis focuses on identifying factors influencing the referral pathways to LVS.

In this introductory chapter, background information about visual impairment, LVS and referral to LVS will be addressed. Finally, an outline of this thesis and the aims of each sub-study will be provided.

Sight and the visual system

For most people sight is the most important of the five human senses,[1] playing a crucial role in all kinds of activities, such as allocating, grasping and remembering objects, as well as interacting with our surroundings.[2,3] Sight helps us to interpret and to understand the world. The visual system involves the eyes and brain, and this complex system makes sight possible.[2-4] Light is captured through the eyes, which triggers light receptors to send electric signals to the brain. From there, these signals are translated and interpreted, which enables visual perception of the captured environment. An eye disease, optic nerve disorder, brain disorder or injury can disrupt this visual system, resulting in visual impairment.

Definition of visual impairment and prevalence

Visual impairment refers to a condition of irreversible and significant decline or loss of sight, and is one of the leading causes of disability in older people.[5,6] Worldwide, various definitions are used. According to the World Health Organisation (WHO), visual impairment is classified as low vision and blindness, whereby low vision is defined as the best corrected visual acuity in the better eye of <0.3 but ≥0.05 (Snellen notation) and/or visual field of <30° around the central fixation point; and blindness is defined as a visual acuity in the better eye of <0.05 and/or a visual field of ≤10° around the central fixation point.[7] This definition is also used by the Dutch Society of Ophthalmology, as outlined in their LVS referral guideline, specifying who, when and how to refer people with irreversible vision loss to LVS.[8]

Globally, an estimated 590 million people are visually impaired according to the WHO definition, of which the majority is caused by uncorrected refractive errors, unoperated cataract, diabetic retinopathy, glaucoma and age-related macular degeneration.[5,9,10] There is great variety between and within countries with respect to the leading causes of the impairment. Where in low and middle income countries, unoperated cataract is leading cause, in high-income countries, such as the Netherlands, visual impairment is predominately caused by age-related macular degeneration, diabetic retinopathy and

glaucoma.[11] In the Netherlands, the estimated number of people with a visual impairment was 367.000 in 2020, of which 234.000 had low vision and 77.000 were blind.[12,13]

Visual impairment can affect individuals of all types of ages, but in general, the majority of the people affected are aged 50 years or older.[5,9] Furthermore, globally the prevalence of visual impairment is higher in women than in men,[5,14] which can be attributed to different biological and social factors, such as longer life expectancy of women, more risk of developing some eye diseases for women (e.g., cataract), barriers in healthcare access for women and less health-seeking behavior among men, resulting in delayed diagnosis.[15,16]

In the past two decades novel and successful treatments, such as vascular endothelial growth factor inhibitors (anti-VEGF) for retinal exudative disease, became available and have helped to reduce the prevalence rates of low vision and blindness.[17,18] However, due to the world's growing and ageing population, the expected absolute number of people with visual impairment is still increasing.[5]

Impact of visual impairment

Visual impairment has a detrimental impact on almost all aspects of an individual's life. Practical aspects of daily living are affected, such as impaired reading,[19] mobility and transportation,[20] resulting in reduced independence and engagement in activities of daily living,[21] along with social isolation[19] and an increased risk of fall-related injuries and fractures.[22] Additionally, it has been repeatedly linked to decreased mental well-being and a higher risk of anxiety and depression.[23,24]

Furthermore, visual impairment has been frequently associated with reduced employment and productivity rates compared to the general population.[25-27] Despite positive developments for people with visual impairment in the past few decades, such as advancements in assistive technology[28] and (vocational) rehabilitation,[29] they often experience barriers in their job search, have problems keeping a job[26] or are underemployed.[30]

Research has shown that all of these factors can significantly and negatively influence an individual's well-being, quality of life and functioning.[31] At a societal level, visual impairment leads to high economic costs, due to work productivity losses and increased healthcare utilization.[32]

Low vision services

LVS may mitigate or reduce the impact of visual impairment by offering practical and mental support and teaching individuals to adapt to or compensate for their visual impairment through different interventions.[33-37] They refer to services such as provision, advice and training in the use of optical (e.g., magnifiers, telescopes) and non-optical low vision aids (LVAs) (e.g., braille books, writers, reading stands, lamps) by low vision optometrists, provision, advice and training in electronic assistive products (e.g., smartphones, tablets) by ICT trainers, independence training in activities of daily life and orientation and mobility

training by occupational therapists, or guidance on acceptance or adaptation to the visual impairment by social workers and psychologists. LVS are aimed at helping people with visual impairment from their early childhood to their late adulthood – depending on its onset – ensuring their optimal participation in society, to gain back independence, and promoting their quality of life and functioning. As visual impairment can affect different components of vision (e.g., visual acuity, peripheral vision), LVS interventions should be adjusted to each individual's specific needs and priorities, according to the WHO.[33]

Research has found a positive direction of the effect of LVS on, among others, enhancing visual functioning, reducing mental distress and improving quality of life.[37] Furthermore, LVS have been proven to have an added value for society, i.e. some of the interventions have been shown to be cost-effective from a societal perspective.[38]

Globally, there are great differences in how LVS are offered and which interventions they include.[34-37] Nearly no country is comparable to another with respect to its LVS system and not every country even offers LVS. In some countries LVS are offered by single services and in a segmented form, where, for example, one organization prescribes and gives training in the utilization of LVAs, whereas another organization offers psychological therapy. In other countries, LVS are offered by a multidisciplinary service, meaning that the full range of services are offered by one organization and different professionals, such as low vision optometrists, psychologists and occupational therapists, who work together in a multidisciplinary team. Furthermore, LVS may be offered by inpatient or outpatient services, in specialized centers or are sometimes embedded in ophthalmic hospital departments. LVS may be provided nationwide with full geographical coverage or may be offered more locally in only certain parts of a country. Countries also differ with respect to funding. In some countries, LVS are partly or fully funded by government, in other countries people with LVS needs are supposed to pay for the services by themselves. They may be offered by for-profit, nonprofit, or charity organizations.

Low vision services in the Netherlands

In the Netherlands, LVS are offered by three nonprofit multidisciplinary LVS organizations, namely Royal Dutch Visio, Bartiméus and the Robert Coppes Foundation, and by for-profit low vision optometrists.[8] The first two are large organizations for all kind of visual impairments, the third is a small organization, with a focus on people with a visual impairment and multiple additional disabilities, such as psychiatric disorders, brain injuries and cognitive impairments. All three organizations offer a wide range of inpatient or outpatient multidisciplinary LVS, including advice and training in LVAs and other disability assistance devices, training in (auto)mobility and orientation and practical life skills, advice for optimal lighting, computer skills training, social skills training and psychological support. Low vision optometry is a specialized field within optometry, where low vision optometrists have been trained in prescribing and fitting optical LVAs after a

functional examination of the visual system. Low vision optometrists work in hospitals, multidisciplinary LVS organizations, specialized optical shops and companies that provide the delivery of aids. They also sometimes offer their services at patients' homes.

LVS in the Netherlands is widely covered by health insurance. After a reallocation of care covered by the Exceptional Medical Expenses Act (Algemene Wet Bijzondere Ziektekosten, AWBZ) including sensory disability care, as of 2015 LVS have been covered by the Health Insurance Act (HIA). The HIA stipulates that everyone living and/or working in the Netherlands is obliged and has the right to take out a basic statutory health insurance.[39,40] This basic insurance covers curative care, among which inpatient and outpatient LVS and often LVAs. Each year insured individuals have to pay the first 385 EUR of all healthcare expenses relating to curative care out of pocket, the 'compulsory deductible'. For healthcare that is not covered by basic insurance, insurers offer an extra (voluntary) health insurance package. With this, individuals can choose to cover additional care, such as dental care or some types of LVAs.

Referral to low vision services in the Netherlands

The Netherlands is one of the few countries worldwide that has a nationwide referral guideline to support the referral process to LVS.[41-43] The referral guideline 'vision disorders: rehabilitation and referral' of the Dutch Society of Ophthalmology serves as a tool for medical specialists to identify people who may benefit from LVS and who should be referred.[8] It is primarily aimed at ophthalmologists, but all medical specialists, such as rehabilitation physicians and neurologists, are authorized to refer patients.

The referral guideline was first published in 2004 and revised two times after that, in 2011 and in 2020.[8,44,45] This thesis refers to the 2011 guideline as it was valid for the data used in this study.[45] This guideline advises referral to multidisciplinary LVS for people with a decimal visual acuity of <0.3 and/or a visual field of <30° around the central point of fixation and/or an evident request for assistance when therapeutic options in regular ophthalmic practice are not sufficient. If patients are already known by the multidisciplinary LVS organizations, a referral by a general practitioner is sufficient. In addition, low vision specialists are allowed to refer patients if their ophthalmologist gives permission.

To receive multidisciplinary LVS, people require an official referral by a medical specialist. However, patients' initial contact with a multidisciplinary LVS organization is sometimes by self-referral, meaning that they reach out to a multidisciplinary LVS organization for help by themselves, after which an official referral by their medical specialist is requested.

The referral guideline also advices referral to for-profit low vision optometrists. Patients should be referred to a low vision optometrist when their visual functioning can be (partially) improved or compensated with optical aids. Otherwise, if low vision optometry is not sufficient for fulfilling the patients' additional needs, referral to multidisciplinary LVS organizations is recommended.

Barriers and facilitators in the referral pathways to low vision services

Despite international LVS referral guidelines and despite the essential role LVS can play for individuals with visual impairment, barriers in the referral pathways to LVS have been identified in various studies worldwide.[46-54] They have brought to attention service access may be challenged by barriers, which can be categorized into the individual, interpersonal, organizational, community, and public policy level according a social ecological approach.[55-57] Such an approach posits that individuals are interrelated with their environment and that there are multiple levels of influence (Figure 1). These levels are interactive and reinforcing, shaping individual (health) behaviors and outcomes.

Barriers that may hinder LVS receipt on an individual level are lack of awareness about LVS[47,58] and misconceptions about LVS in patients,[59] as well as having other health complaints as a patient.[60,61] Lack of social support as a patient may form a barrier on an interpersonal level,[54] whereas lack of awareness on referral criteria in providers[62] and lack of referral by providers[63] may be barriers on an organizational level. Furthermore, experienced societal stigma by patients[60,64] and lack of transportation[63] may hinder LVS access on a community level, and lack of full geographical service provision[65] and costs of LVS[49,66] on a public policy level. Besides that, studies also have identified facilitators that contribute to LVS access, such as more severe vision loss[52] and higher education[67] on an individual level, and following referral guidelines as a professional[68] on an organizational level.

In the Netherlands, an estimated 10-15% of the estimated 367.000 visually impaired people receive multidisciplinary LVS annually.[69-76] People with visual impairment might not use multidisciplinary LVS every year, which may partially explain the low percentage of service utilization. Explanations might also be found in the fact that patients might have utilized low vision optometry only, which might have been sufficient for them, and, in the earlier mentioned study outcomes on barriers and facilitators in LVS access. However, there still seems to be a discrepancy in the need and the actual uptake of these services, indicating unknown barriers in the referral pathways to LVS. Additionally, as LVS provision differs largely between countries and because of the unique Dutch LVS approach, incorporating low vision optometry before multidisciplinary LVS and nationwide provision, there might be barriers and facilitators specific for the Dutch healthcare context.

Furthermore, literature on LVS access to date has also mainly focused on low income countries and/or countries where LVS is not provided nationwide or with less financial coverage of LVS.[48-50,52,60-62,64,77,78] Consequently, there is a general lack of research from high-income countries with different types of healthcare systems on barriers and facilitators at the individual, interpersonal, organizational, community, and public policy level. More insight from this healthcare systems' perspective will provide more knowledge on barriers and facilitators at all levels.

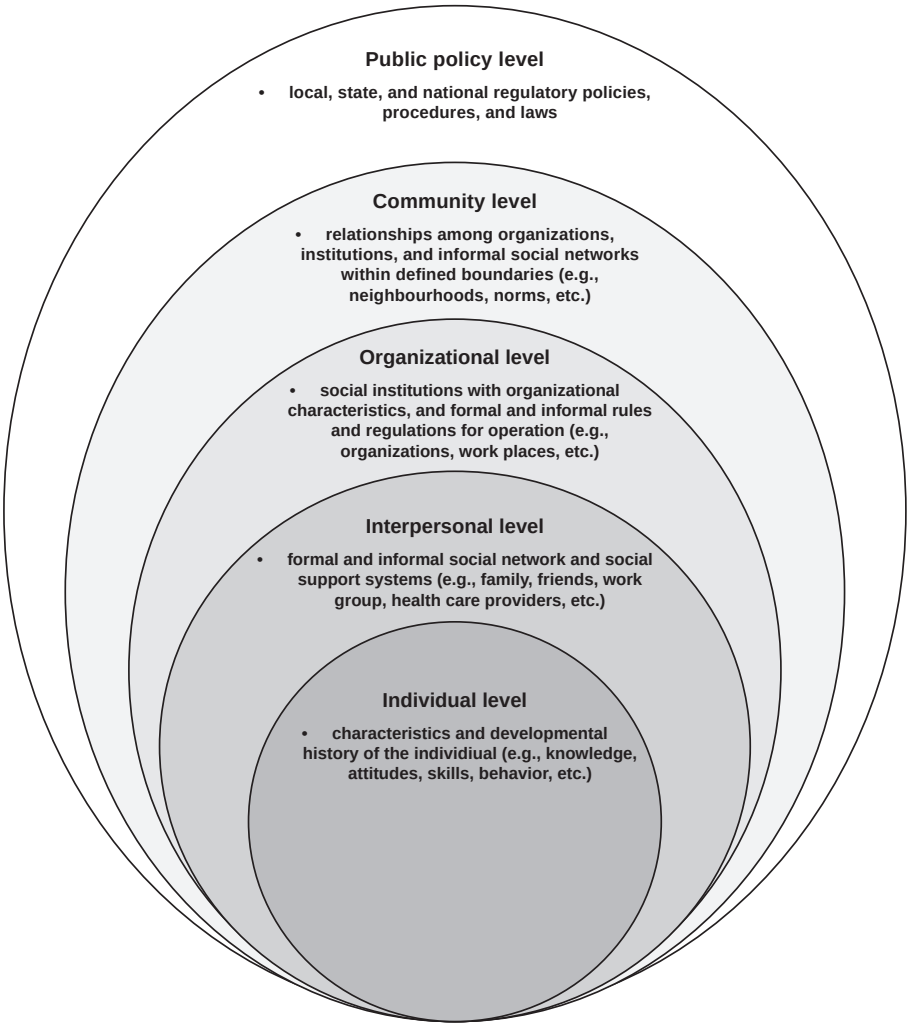

FIGURE 1. Social Ecological Model. Adapted from McLeroy et al.[55]

Research with population-based healthcare claims data appears to be promising in giving insight into the delivery of healthcare services.[79-81] Claims data of health insurers are administrative data collected for billing purposes of healthcare activities. As they reflect the actually delivered reimbursable healthcare and represent actual patient populations that received this care, they may include valuable information about barriers and facilitators in LVS delivery. While in clinical ophthalmic studies, research based on claims data has been quite established,[79,82,83] there are very few studies that have examined barriers and facilitators in LVS access based on this type of data.[65]

In general, with more insight into factors influencing referral pathways to LVS, internal and external influences involved may be better understood. Based on this knowledge, advice for clinical practice can be formulated so that individuals with LVS needs receive the right care at the right moment and at the right place. This may lead to improvement of suboptimal referral pathways and the overall optimization of the quality of care for people with visual impairment.

Aim and outline of this thesis

The aim of the Visually Impaired Person Path (VIP-Path) study described in the present thesis was to identify factors influencing the referral pathways to LVS in high-income countries. In the five studies described in this thesis, we employed different methods and perspectives to gain more insight into barriers and facilitators in the LVS referral pathways in two high-income countries, namely the Netherlands and Germany, by taking the Social Ecological Model into account.

In the first study, described in ***Chapter 2***, both the perspectives of people with visual impairment and eye care professionals in the Netherlands were examined regarding barriers and facilitators in multidisciplinary LVS referral procedures and service delivery. Semi-structured interviews were performed with patients with macular degeneration, diabetic retinopathy and/or glaucoma, and different healthcare professionals including ophthalmologists, optometrists and LVS professionals.

The second study, described in ***Chapter 3***, investigates the national trends between 2015 and 2018 in multidisciplinary LVS utilization and identified sociodemographic, clinical, contextual characteristics and general healthcare utilization of patients associated with the downward trend in the uptake of multidisciplinary LVS in the Netherlands. This retrospective study was based on a Dutch national health insurance claims database retrieved from Vektis C.V..

The objective of the third study, described in ***Chapter 4,*** is to investigate which characteristics predict receiving multidisciplinary LVS in a high-income country, based on healthcare claims data. Specifically, predictors regarding sociodemographic, clinical and contextual characteristics of multidisciplinary LVS patients, as well as general healthcare utilization of patients receiving multidisciplinary LVS, were explored. Health insurance claims data between 2015 and 2018 of adult patients with eye diseases related to severe vision loss in the Netherlands were retrieved (Vektis C.V.).

In the fourth study, described in ***Chapter 5***, we zoomed in on the association between physical comorbidity and mental comorbidity and receiving multidisciplinary LVS, with the aim to get more insight into the role of having other conditions in addition to the eye disease in multidisciplinary LVS access. For this study, we also used the Dutch health insurance claims database with data between 2015 and 2018 of adult patients with eye diseases related to severe vision loss (Vektis C.V.).

Chapter 6 describes a study performed in an urban setting in Germany, which aimed to investigate LVS in terms of LVA provision, and trends in user characteristics. Analyses were based on population-based healthcare claims data spanning a four-year period (2014-2017) of the city of Cologne, North Rhine-Westphalia.

The final chapter, ***Chapter 7***, contains a summary and discussion of the main results of the studies and methods used and provides implications for present clinical practice, including referrals to LVS. Besides that, ideas for the direction of future research are presented.

The thesis is completed with an ***addendum***, including a Dutch summary, a list of abbreviations, publications and contributing authors, a PhD portfolio, acknowledgements and a curriculum vitae.

REFERENCES

1. Enoch J, McDonald L, Jones L, Jones PR, Crabb DP. Evaluating Whether Sight Is the Most Valued Sense. *JAMA Ophthalmol.* 2019;137(11):1317-20.
2. Smith EE, Kosslyn SM. Cognitive psychology : mind and brain. [Repr.] ed. Upper Saddle River, N.J: Pearson Prentice Hall; 2009.
3. Kalat JW. Biological Psychology: Wadsworth, Cengage Learning; 2009.
4. Tan H, Van der Pol B, Stilma JS. Leerboek oogheelkunde: Bohn Stafleu van Loghum; 2013.
5. Bourne R, Steinmetz JD, Flaxman S, Briant PS, Taylor HR, Resnikoff S, et al. Trends in prevalence of blindness and distance and near vision impairment over 30 years: an analysis for the Global Burden of Disease Study. *Lancet Glob Health.* 2021;9(2):e130-e43.
6. Prince MJ, Wu F, Guo Y, Gutierrez Robledo LM, O'Donnell M, Sullivan R, et al. The burden of disease in older people and implications for health policy and practice. *Lancet.* 2015;385(9967):549-62.
7. World Health Organisation. 9D90 Vision impairment including blindness. 2022. In: International statistical classification of diseases 11th Revision [Internet]. [cited 2022 Nov 11]. Available from: https://icd.who.int/browse/2024-01/mms/en#1103667651.
8. Nederlands Oogheelkundig Gezelschap. Visuele beperkingen - verwijzing en revalidatie [Vision disorders: referral and rehabilitation] 2020 [cited 2022 Jan 8]. Available from: https://richtlijnendatabase.nl/richtlijn/visuele_beperkingen_-_verwijzing_en_revalidatie/verwijzing_voor_revalidatie_bij_visuele_beperkingen.html.
9. Flaxman SR, Bourne RRA, Resnikoff S, Ackland P, Braithwaite T, Cicinelli MV, et al. Global causes of blindness and distance vision impairment 1990-2020: a systematic review and meta-analysis. *Lancet Glob Health.* 2017;5(12):e1221-e34.
10. Burton MJ, Ramke J, Marques AP, Bourne RRA, Congdon N, Jones I, et al. The Lancet Global Health Commission on Global Eye Health: vision beyond 2020. *Lancet Glob Health.* 2021;9(4):e489-e551.
11. World Health Organisation (WHO). Blindness and vision impairment 2023 [cited 2022 Jan 8]. Available from: https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment.
12. Limburg H, Keunen JE. Blindness and low vision in The Netherlands from 2000 to 2020-modeling as a tool for focused intervention. *Ophthalmic Epidemiol.* 2009;16(6):362-9.
13. Keunen JEE, Verezen CA, Imhof SM, Rens GHMBv, Asselbergs MB, Limburg JJH. Toename in de vraag naar oogzorg in Nederland 2010-2020. *Ned Tijdschr Geneeskd.* 2011;155(A3461).
14. Bourne RRA, Flaxman SR, Braithwaite T, Cicinelli MV, Das A, Jonas JB, et al. Magnitude, temporal trends, and projections of the global prevalence of blindness and distance and near vision impairment: a systematic review and meta-analysis. *Lancet Glob Health.* 2017;5(9):e888-e97.
15. Lewallen S, Mousa A, Bassett K, Courtright P. Cataract surgical coverage remains lower in women. *Br J Ophthalmol.* 2009;93(3):295-8.
16. Rius Ulldemolins A, Benach J, Guisasola L, Artazcoz L. Why are there gender inequalities in visual impairment? *Eur J Public Health.* 2018;29(4):661-6.
17. Mitchell P, Liew G, Gopinath B, Wong TY. Age-related macular degeneration. *Lancet.* 2018;392(10153):1147-59.
18. Hang A, Feldman S, Amin AP, Ochoa JAR, Park SS. Intravitreal Anti-Vascular Endothelial Growth Factor Therapies for Retinal Disorders. *Pharmaceuticals.* 2023;16(8):1140.

19. Lamoureux EL, Fenwick E, Moore K, Klaic M, Borschmann K, Hill K. Impact of the severity of distance and near-vision impairment on depression and vision-specific quality of life in older people living in residential care. *Invest Ophth Vis Sci.* 2009;50(9):4103-9.
20. Elsman EBM, Koel M, van Nispen RMA, van Rens GHMB. Quality of Life and Participation of Children With Visual Impairment: Comparison With Population Reference Scores. *Invest Ophthalmol Vis Sci.* 2021;62(7):14-.
21. Kempen GI, Ballemans J, Ranchor AV, van Rens GH, Zijlstra GA. 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. *Qual Life Res.* 2012;21(8):1405-11.
22. de Boer MR, Pluijm SM, Lips P, Moll AC, Volker-Dieben HJ, Deeg DJ, et al. Different aspects of visual impairment as risk factors for falls and fractures in older men and women. *J Bone Miner Res.* 2004;19(9):1539-47.
23. Rees G, Fenwick EK, Keeffe JE, Mellor D, Lamoureux EL. Detection of depression in patients with low vision. *Optom Vis Sci.* 2009;86(12):1328-36.
24. van der Aa HPA, Comijs HC, Penninx BWJH, van Rens GHMB, van Nispen RMA. Major Depressive and Anxiety Disorders in Visually Impaired Older Adults. *Invest Ophthalmol Vis Sci* 2015;56(2):849-54.
25. Brunes A, Heir T. Visual impairment and employment in Norway. *BMC Public Health.* 2022;22(1):648.
26. Goertz YHH, van Lierop BAG, Houkes I, Nijhuis FJN. Factors Related to the Employment of Visually Impaired Persons: A Systematic Literature Review. *J Vis Impair Blind.* 2010;104(7):404-18.
27. Daniëls R, van Nispen RM, de Vries R, Donker-Cools BHPM, Schaafsma FG, Hoving JL. Predictors for work participation of people with visual impairments: A systematic review and meta-analysis. *Ophthal Physl Opt.* 2023;43(5):1223-54.
28. Aqel MOA, Issa A, Elsharif AA, Ghaben S, Alajerami YSM, Khalaf H, et al., editors. Review of Recent Research Trends in Assistive Technologies for Rehabilitation. 2019 International Conference on Promising Electronic Technologies (ICPET); 2019 23-24 Oct. 2019.
29. Trauzettel-Klosinski S. Current methods of visual rehabilitation. *Dtsch Arztebl Int.* 2011;108(51-52):871-8.
30. Mojon-Azzi SM, Sousa-Poza A, Mojon DS. Impact of low vision on employment. *Ophthalmologica.* 2010;224(6):381-8.
31. Langelaan M, de Boer MR, van Nispen RM, Wouters B, Moll AC, van Rens GH. Impact of visual impairment on quality of life: a comparison with quality of life in the general population and with other chronic conditions. *Ophthalmic Epidemiol.* 2007;14(3):119-26.
32. Köberlein J, Beifus K, Schaffert C, Finger RP. The economic burden of visual impairment and blindness: a systematic review. *BMJ open.* 2013;3(11):e003471.
33. World Health Organization. Package of eye care interventions: World Health Organization; 2022 [cited 2024 Apr 4]. Available from: https://iris.who.int/bitstream/handle/10665/354256/9789240048959-eng.pdf?sequence=1.
34. Owsley C, McGwin G, Jr., Lee PP, Wasserman N, Searcey K. Characteristics of low-vision rehabilitation services in the United States. *Arch Ophthalmol.* 2009;127(5):681-9.
35. Markowitz SN. Principles of modern low vision rehabilitation. *Can J Ophthalmol.* 2006;41(3):289-312.
36. Lim YE, Vukicevic M, Koklanis K, Boyle J. Low Vision Services in the Asia-Pacific Region: Models of Low Vision Service Delivery and Barriers to Access. *J Vis Impair Blind.* 2014;108(4):311-22.

37. van Nispen RMA, Virgili G, Hoeben M, Langelaan M, Klevering J, Keunen JEE, et al. Low vision rehabilitation for better quality of life in visually impaired adults. *Cochrane Database Syst Rev.* 2020(1).
38. van der Aa HPA, van Rens G, Verbraak FD, Bosscha M, Koopmanschap MA, Comijs HC, et al. Economic evaluation of an e-mental health intervention for patients with retinal exudative diseases who receive intraocular anti-VEGF injections (E-PsEYE): protocol for a randomised controlled trial. *BMJ Open.* 2017;7(11):e018149.
39. Kroneman M, Boerma W, van den Berg M, Groenewegen P, de Jong J, van Ginneken E. Netherlands: Health System Review. *Health Syst Transit.* 2016;18(2):1-240.
40. Dutch Healthcare Authority. What are our tasks? How does the Dutch healthcare system work? [cited 2023 Mar 15]. Available from: https://english.zorginstituutnederland.nl/.
41. American Optometric Association. Clinical Practice Guidelines n.d. [cited 2022 Nov 8]. Available from: https://www.aoa.org/practice/clinical-guidelines/clinical-practice-guidelines?sso=y.
42. Sinclair A, Ryan B. Low vision: The essential guide for ophthalmologists: The Guide Dogs for the Blind Association; 2021 [cited 2022 Nov 8]. Available from: https://www.rcophth.ac.uk/resources-listing/low-vision-the-essential-guide-for-ophthalmologists/.
43. Low Vision Academy. Guidelines for the visual rehabilitation of the visually impaired 2016 [cited 2022 Nov 8]. Available from: https://en.lowvisionacademy.org/2014/09/16/guidelines-for-the-visual-rehabilitation/.
44. Nederlands Oogheelkundig Gezelschap. Richtlijn Verwijzing van slechtzienden en blinden: Boer MR de, Jansonius N, Langelaan M, en Rens GHMB van (red). Van Zuiden Communications bv. Alphen aan de Rijn. 2004.
45. van Rens GHMB, Vreeken HL, van Nispen RMA. Richtlijn visusstoornissen revalidatie en verwijzing [Guideline vision disorders: rehabilitation and referral] 2011 [cited 2020 Sep 20]. Available from: http://www.vivis.nl/wp-content/uploads/2019/10/Richtlijn-visusstoornissen-revalidatie-en-verwijzing.pdf.
46. Takashi S, Kumiko I. Barriers to the Utilization of Low-Vision Rehabilitation Services among Over-50-Year-Old People in East and Southeast Asian Regions: A Scoping Review. *Int J Environ Res Public Health.* 2023;20(23).
47. Abraham CH, van Staden D, Rampersad N. Barriers and enablers to low vision care and rehabilitation in sub-Saharan Africa within a global context. *Clin Exp Optom.* 2023:1-11.
48. Oviedo-Cáceres MdP, Arias-Valencia S, Hernández-Quirama A, Ruiz-Rodríguez M, Guisasola-Valencia L. Intersectionality and access to visual rehabilitation services: Experiences of people with low vision, a qualitative study. *Br J Vis Impair.* 2022;41(4):831-42.
49. Kyeremeh S, Mashige KP. Availability of low vision services and barriers to their provision and uptake in Ghana: practitioners' perspectives. *Afr Health Sci.* 2021;21(2):896-903.
50. Sivakumar P, Vedachalam R, Kannusamy V, Odayappan A, Venkatesh R, Dhoble P, et al. Barriers in utilisation of low vision assistive products. *Eye.* 2020;34(2):344-51.
51. Shah P, G. Schwartz S, Gartner S, U. Scott I, Flynn H. Low vision services: a practical guide for the clinician2018. 251584141877626 p.
52. Goldstein JE, Guo X, Boland MV, Swenor BK. Low Vision Care - Out of Site. Out of Mind. *Ophthalmic Epidemiol.* 2020;27(4):252-8.
53. Lam N, Leat SJ. Reprint of: Barriers to accessing low-vision care: the patient's perspective. *Can J Ophthalmol.* 2015;50 Suppl 1:S34-9.
54. Khimani KS, Battle CR, Malaya L, Zaidi A, Schmitz-Brown M, Tzeng H-M, et al. Barriers to Low-Vision Rehabilitation Services for Visually Impaired Patients in a Multidisciplinary Ophthalmology Outpatient Practice. *J Ophthalmol.* 2021;2021:1-7.

55. McLeroy KR, Bibeau D, Steckler A, Glanz K. An ecological perspective on health promotion programs. *Health Educ Q.* 1988;15(4):351-77.
56. Richard L, Potvin L, Kishchuk N, Prlic H, Green LW. Assessment of the integration of the ecological approach in health promotion programs. *Am J Health Promot.* 1996;10(4):318-28.
57. Golden SD, Earp JAL. Social Ecological Approaches to Individuals and Their Contexts:Twenty Years of Health Education & Behavior Health Promotion Interventions. *Health Educ Behav.* 2012;39(3):364-72.
58. Walter C, Althouse R, Humble H, Leys M, Odom J. West Virginia survey of visual health: Low vision and barriers to access. *Vis Impair Res.* 2004;6(1):53-71.
59. Pollard TL, Simpson JA, Lamoureux EL, Keeffe JE. Barriers to accessing low vision services. *Ophthalmic Physiol Opt.* 2003;23(4):321-7.
60. Matti AI, Pesudovs K, Daly A, Brown M, Chen CS. Access to low-vision rehabilitation services: barriers and enablers. *Clin Exp Optom.* 2011;94(2):181-6.
61. O'Connor PM, Mu LC, Keeffe JE. Access and utilization of a new low-vision rehabilitation service. *Clin Exp Optom.* 2008;36(6):547-52.
62. Sarika G, Venugopal D, Sailaja MVS, Evangeline S, Krishna Kumar R. Barriers and enablers to low vision care services in a tertiary eye care hospital: A mixed method study. *Indian J Ophthalmol.* 2019;67(4):536-40.
63. Khimani KS, Battle CR, Malaya L, Zaidi A, Schmitz-Brown M, Tzeng HM, et al. Barriers to Low-Vision Rehabilitation Services for Visually Impaired Patients in a Multidisciplinary Ophthalmology Outpatient Practice. *J Ophthalmol.* 2021;2021:6122246.
64. Kaldenberg J. Low vision rehabilitation services: Perceived barriers and facilitators to access for older adults with visual impairment. *Br J Occup Ther.* 2019;82:466-74.
65. Basilious A, Basilious A, Mao A, Hutnik CML. Trends in low vision care provided by ophthalmologists in Ontario between 2009 and 2015. *Can J Ophthalmol.* 2019;54(2):229-36.
66. Gold D, Simson H. Identifying the needs of people in Canada who are blind or visually impaired: Preliminary results of a nation-wide study. *International Congress Series.* 2005;1282:139-42.
67. Overbury O, Wittich W. Barriers to low vision rehabilitation: the Montreal Barriers Study. *Invest Ophthalmol Vis Sci.* 2011;52(12):8933-8.
68. Kaleem MA, West SK, Im LT, Swenor BK. Referral to Low Vision Services for Glaucoma Patients: Referral Patterns and Characteristics of Those Who Refer. *J Glaucoma.* 2017;26(2):e115-e20.
69. Royal Dutch Visio. Visio Jaardocument 2015 [Visio annual report 2015] [cited 2020 Sep 1]. Available from: https://adoc.pub/jaarverslag-koninklijke-visio-expertisecentrum-voor-slechtzi0dc332180e2c7930faceee57c715e3a346994.html.
70. Royal Dutch Visio. Visio Jaardocument 2017 2017 [cited 2020 Sep 1]. Available from: https://www.visio.org/visio.org/media/Visio/Downloads/tg_jaarbericht_visio_-2017.pdf.
71. Royal Dutch Visio. Visio in 2018 2018 [Available from: https://www.visio.org/visio.org/media/Visio/Downloads/Visio_jaarverslag_2018_DEF.pdf.
72. Royal Dutch Visio. Visio in 2019 2019 [cited 2014 May 5]. Available from: https://www.visio.org/visio.org/media/Visio/Downloads/TG_Jaarbericht-2019.pdf.
73. Royal Dutch Visio. Visio in beeld 2022 2022 [cited 2024 May 5]. Available from: https://jaarbeeld.visio.org/assets/files/pdf-versie-van-visio-in-beeld-2022.pdf.
74. Bartiméus. Jaarverantwoording Stichting Bartiméus Sonneheerdt 2015 2015 [Available from: http://docplayer.nl/32368810-Jaarverantwoording-stichting-bartimeus-sonneheerdt-1.html.

75. Robert Coppes Foundaton. Jaarverslag 2020 [Annual report 2020] 2020 [cited 2024 May 5]. Available from: https://www.robertcoppes.nl/wp-content/uploads/2021/07/Jaardocument-2020-DEFINITIEF.pdf.
76. Robert Coppes Foundation. Robert Coppes Stichting 2021 in beeld [Robert Coppes Foundation 2021 in picture] 2021 [cited 2024 May 5]. Available from: https://robertcoppes.nl/wp-content/uploads/2022/07/RCS-in-beeld-2021.pdf.
77. Khimani K, Redmon C, Malaya L, Zaidi A, Schmitz-Brown M, Tzeng H-M, et al. Barriers to low vision care rehabilitation services for visually impaired patients in a multidisciplinary ophthalmology outpatient practice. *Investig Ophthalmol Vis Sci.* 2021;62(8):6122246.
78. Lam N, Leat SJ, Leung A. Low-vision service provision by optometrists: a Canadian nationwide survey. *Optom Vis Sci.* 2015;92(3):365-74.
79. Sloan FA, Yashkin AP, Chen Y. Gaps in receipt of regular eye examinations among medicare beneficiaries diagnosed with diabetes or chronic eye diseases. *Ophthalmology.* 2014;121(12):2452-60.
80. Olthof M, Groenhof F, Berger MY. Continuity of care and referral rate: challenges for the future of health care. *Fam Pract.* 2019;36(2):162-5.
81. Beernaert K, Cohen J, Deliens L, Devroey D, Vanthomme K, Pardon K, et al. Referral to palliative care in COPD and other chronic diseases: A population-based study. *Respiratory Medicine.* 2013;107(11):1731-9.
82. Stein JD, Lum F, Lee PP, Rich WL, 3rd, Coleman AL. Use of health care claims data to study patients with ophthalmologic conditions. *Ophthalmology.* 2014;121(5):1134-41.
83. Tseng VL, Yu F, Lum F, Coleman AL. Risk of fractures following cataract surgery in medicare beneficiaries. *JAMA.* 2012;308(5):493-501.

CHAPTER 2

Barriers and facilitators in the referral pathways to low vision services from the perspective of patients and professionals: a qualitative study

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BMC Health Services Research. 2023;23(1):64.
doi: 10.1186/s12913-022-09003-0

ABSTRACT

Background

Underutilization of and lack of access to low vision services (LVS) has been reported internationally. The purpose of this study was to identify barriers and facilitators in multidisciplinary LVS referral procedures and service delivery from both the perspective of people with visual impairment and professionals from different eye care providers in the Netherlands.

Methods

A qualitative study in the Netherlands was conducted. Barriers and facilitators were explored through semi-structured interviews with older adults with macular degeneration, diabetic retinopathy and/or glaucoma (n=14), and healthcare professionals including ophthalmologists and LVS professionals (n=16). Framework analysis was used for analyzing the interviews with ATLAS.ti software.

Results

According to both patients and professionals, facilitators in multidisciplinary LVS access and utilization are having motivation, self-advocacy, high participation needs and social support, as well as being negatively impacted by the impairment. Both samples found having good communication skills and informing patients about multidisciplinary LVS as a healthcare provider to facilitate access. A long patient-provider relationship and the Dutch healthcare system were also mentioned as facilitators. Professionals additionally found long disease duration and the presence of low vision optometric services in the ophthalmic practice to promote access.

Barriers that were reported by patients and professionals are lack of motivation, self-advocacy and acceptance of the impairment in patients. In addition, having low participation needs as a patient, lack of information provision by providers and time constraints in the ophthalmic practice were mentioned as barriers. Professionals also reported lack of social support, short disease duration of patients, a short patient-provider relationship and lack of coordination of care in the ophthalmic practice to hinder access.

Conclusions

Findings suggest that providers' lack of information provision about multidisciplinary LVS, especially to patients who are less assertive, hamper referral to multidisciplinary LVS. Providers should have attention for patients' multidisciplinary LVS needs and actively inform them and their social network about multidisciplinary LVS to facilitate access. Educating and training providers about how and when to address multidisciplinary LVS may help to reduce barriers in the referral pathways. In addition, referral procedures may benefit from tools that make providers more aware of multidisciplinary LVS.

INTRODUCTION

Visual impairment is associated with difficulties in participating in daily activities,[1,2] increased risk of depression,[3,4] anxiety,[4] fatigue,[5] fall incidents and bone fractures.[6] Consequently, it can negatively affect the quality of life of individuals. According to World Health Organizations (WHO) definition, visual impairment is defined as mild to severe vision impairment or blindness.[7] Globally, an estimated 590 million people[8] are currently affected by visual impairment. Those with functional complaints are more at risk of having to deal with the adverse impact of the impairment.

People with a visual impairment may benefit from low vision services (LVS), which are aimed at helping people to gain (back) independence, to fully participate in daily life activities and in society, thereby enhancing their quality of life.[9,10] These services may include, but are not limited to prescription of and training in the use of low vision aids (LVAs), training in orientation and mobility skills, support in daily life activities and guidance on acceptance or adaptation to the visual impairment.[11-13] They are, among others, offered by social workers, optometrists, low vision optometrists, psychologists and occupational therapists. Some LVS have proven to be effective in enhancing the quality of life and visual functioning of adults with severe visual impairment.[13] Furthermore, from an international perspective, different institutions recommend referral to LVS in their clinical practice guidelines for ophthalmologists and optometrists, such as the American Optometric Association (United States),[14] the Royal College of Ophthalmologists (United Kingdom)[15] the Low Vision Academy (Italy)[16] and the Dutch Society of Ophthalmologists (Netherlands).[17] Despite these efforts and supporting literature on the benefits of LVS, international studies report underutilization of and lack of access to LVS.[18-21] There seems to be a mismatch between the potential need and the actual uptake of these services. From the perspective of individuals with visual impairment, healthcare costs, miscommunication with healthcare professionals and stigmatization by other people formed barriers in the access to or utilization of LVS.[22] From the perspective of eye care professionals, insufficient time in the ophthalmic practice, lack of knowledge and experience, and lack of funding for LVS devices seemed to hinder referral.[23,24] From the patients' view, self-advocacy, good communication with the professionals and social support by family and friends were some of the identified facilitators.[22,25] Following referral guidelines was a facilitator identified by professionals.[26]

Existing studies mainly examined either the perspective of patients or healthcare professionals.[22-24,26-31] However, Khimani et al.[32] and Sarika et al.[33] recently showed that investigating both point of views can be beneficial as it generates a broad perspective, which contributes to a better understanding about factors influencing the referral pathways to LVS. Furthermore, earlier studies were mainly conducted in countries with no systematic national provision or financial coverage of LVS and/or with a low income, such as the United States,[25,28,32] Australia,[30,31] Canada,[23] India,[29,33] Colombia[34] and Ghana.[35]

As a consequence, insights to referral barriers and facilitators are particularly lacking from high-income countries in general with different types of healthcare and coverage systems.

This study aimed to explore barriers and facilitators in the referral pathways to multidisciplinary LVS in the Netherlands from both the patient's and the professional's perspective. As LVS in the Netherlands are provided regionally, nationally and are well-funded by health insurance, to the best of our knowledge, this will be the first study in such a context. We focused on individuals aged 50 years or older, which includes the working population, next to those at risk of the most common causes of irreversible visual impairment.[36]

METHODS

Design

We conducted a qualitative exploratory study in the Netherlands, using semi-structured interviews with eye care professionals and patients with visual impairment to examine barriers and facilitators in the referral pathways to multidisciplinary LVS. The study is reported in accordance with the COnsolidated criteria for REporting Qualitative research (COREQ).[37]

Study setting: low vision services in the Netherlands

In the Netherlands, LVS are provided by specialized for-profit low vision optometrists and three nonprofit multidisciplinary LVS organizations, where LVS are offered by, among others, optometrists, advisory professionals, psychologists, social workers and occupational therapists. Low vision optometrists fit, prescribe and give advice about optical LVAs (e.g., magnifiers and telescope glasses) during low vision optometric services that are mainly offered in hospitals, but also at patients' homes or at multidisciplinary LVS organizations. Low vision optometric services in hospitals are sometimes organized in cooperation with a multidisciplinary LVS center. During such combined optometric services, patients also get information by advisory professionals of LVS organizations about which care they provide.

Multidisciplinary LVS organizations in the Netherlands offer the full range of supporting services, including advice and training in disability assistive products (e.g., cane, smartphone), mobility and orientation training and psychological therapy. All LVS are provided regionally and are largely funded by health insurance, with a compulsory deductible of 385 EUR per year (since 2016).[38] Optical aids and other disability assistive products often need to be (partially) paid by patients, next to the compulsory deductible, depending on whether or not health insurers have a contract with the LVAs supplier. For non-contracted LVAs, health insurers remunerate the cost up to a maximum of 80%. According to the guideline of the Dutch Society of Ophthalmology[17] referral to a low vision optometrist needs to be considered when the visual functioning of patients can be (partially) improved or compensated with optical LVAs. Referral to multidisciplinary LVS organizations is recommended for patients with a visual acuity of >0.50 logMAR (6/19 Snellen) and/or a visual field of <30° around the central point of fixation and/or an evident request for assistance when therapeutic options in regular ophthalmic practice are insufficient. Officially, patients need to be referred by a medical specialist (e.g., ophthalmologists) or a low vision optometrist in consultation with an ophthalmologist for LVS utilization at the multidisciplinary LVS organizations. In practice, patients sometimes contact multidisciplinary LVS organizations without being referred (self-referral) and then need to request an official referral by their medical specialist before they can access multidisciplinary LVS.

Study population

Professionals

Eye care professionals from different healthcare institutions were recruited by purposive sampling[39] to reflect diversity in types of professionals and a mix of sex, age and years of work experience. Professionals included were ophthalmologists and LVS professionals. Inclusion criteria for professionals were: (a) contact with patients (50+) with macular degeneration, glaucoma and/or diabetic retinopathy and, (b) involvement in the referral process to multidisciplinary LVS or sufficient knowledge about it by profession. Professionals employed for less than 6 months were excluded from participation.

Recruitment of professionals took place via a multidisciplinary LVS organization, an academic and a non-academic hospital. Potential participants were contacted by email along with an information letter about the study, after which they were called to double check the inclusion criteria.

Patients

Patients were selected by purposive and convenience sampling[39] to reflect ophthalmic diagnoses that most often cause irreversible visual impairment in people aged 50 years or older and the working population, and to reflect a mix of disease duration, sex, age, type of referral to multidisciplinary LVS (self-referral, referral by ophthalmologist) and status of referral (did/did not follow up on referral). Patients were purposively recruited by an academic and two non-academic hospitals and the Netherlands Institute for Health Services, and through convenience sampling by two patient associations for general eye diseases and macular-related eye diseases via their websites and newsletters. Inclusion criteria that were checked by the recruiting institution and by telephone were: (a) 50 years or older; (b) diagnosis of macular degeneration, glaucoma and/or diabetic retinopathy; (c) referral to a multidisciplinary LVS not longer than 6 months ago; (d) first time referral; (e) sufficient mastery of the Dutch language, and (f) cognitively able to participate in an interview. With respect to cognitive impairment, this was checked by the recruiting institution on the basis of clinical patient information, i.e. those with an intellectual disability or a cognitive impairment were excluded from the study. Furthermore, cognitive eligibility was examined by telephone based on how the inclusion conversation went.

An information letter and a participation form was sent to potential participants and they all received oral information by telephone before signing informed consent.

Sample size

On the basis of existing literature on qualitative research design[40,41] and the researchers' experience, we aimed to recruit a total of 30 participants, with 15 respondents for each of the two subgroups of patients and professionals. This sample size was deemed to be sufficient to hold enough information power[41] to contribute substantially to new

understandings of the research topic in the Dutch LVS context. During the whole research process we regularly evaluated the adequacy of the pre-set sample size.

Data-collection

A semi-structured one-on-one interview was scheduled for all eligible participants and conducted by MS; data were collected between September 2019 and April 2021. Interviews with professionals were conducted face-to-face at their workplace. However, because of COVID-19 pandemic government regulations between March 2020 and 2021, patients were interviewed by telephone.

An interview scheme was developed for each of the two subgroups separately and was based on findings from prior studies,[22,24-26] and on the Social Ecological Model[42,43] (available upon request). According to a social ecological approach of health promotion, health is a function of an individual and his/her environment. It can be used to identify the factors that contribute to a certain health-problem on individual, interpersonal, organizational, community and public-policy level and was recently used by Kaldenberg[25] in a similar study.

Both interview schemes addressed participants' personal experiences and behaviors relating to barriers and facilitators in the referral pathways. The interview started with (1) an introduction by the interviewer, explaining the study and interview structure, followed by (2) general questions about the participant, asking about (working) background, and visual impairment and health characteristics (patients), (3) questions about the referral pathways, referral procedures, reasons for patients' (self-)referral and (not) following up on referral, information provision, communication between patient and provider and registration at multidisciplinary LVS, (4) general questions about the referral pathways, probing most relevant barriers and facilitators and advices for clinical practice, and (5) concluding questions with a summary and verification of the topics discussed during the interview. Interview schemes were pilot tested in advance.

The interviews took between 60 and 120 minutes. Patients received a gift certificate for their participation.

Data-analysis

Interviews were audio recorded and transcribed verbatim. The transcribed interviews were summarized and were sent to participants for member checking.[44] This led to some additions and adjustments.

Transcribed interviews were analyzed with framework analysis[45-47] in ATLAS.ti 8 software. After reading all the transcripts and making notes to get familiar with the data (step 1), four interviews were coded independently and inductively by two researchers (MS and AvdH) and were classified into main themes and subthemes (step 2). After the researchers agreed on the coding, which was accomplished by face-to-face discussion, an analytical framework was developed that was purposefully linked to the Social Ecological

model which was used as a basis for the interviews (step 3). All transcripts were then reviewed to apply the analytical framework and to chart the data into a framework matrix (step 4 and 5). Finally (step 6), we mapped and interpreted the data and established relationships by grouping themes around the levels of the Social Ecological Model.[42]

RESULTS

Response and characteristics

Sixteen professionals (female 40%) participated in this study (Table 1). The mean age was 47 years (range 30-64). Professionals were ophthalmologists and LVS professionals such as (low vision) optometrists, eligibility assessors/administrators, an advisory professional, a clinical physicist and a manager. The average working experience of the professionals was 15.5 years.

Fourteen patients participated in this study (female 70%). The mean age was 74 (range 55-96). Almost two thirds of patients had macular degeneration as the cause of vision loss, followed by glaucoma and diabetic retinopathy. Half of all patients initiated their own referral by asking their medical specialist or by contacting a multidisciplinary LVS themselves after which a post-hoc referral was arranged. The other half was referred by indication of a medical specialist. All patients followed up on their referral and utilized multidisciplinary LVS. On average, patients had been referred 2 years ago.

Barriers and facilitators

Barriers and facilitators according to the Social Ecological Model are presented in Table 2. In order to give an indication about the number of described experiences, following system in reporting the findings has been used: One participant; Some - up to a quarter of the participants; Several - between a quarter and half of the participants; Half of the participants; The majority - between half and three quarters of the participants; (Almost) all of the participants.

Individual level

Motivation

Patients' motivation was identified as an important barrier and facilitator for multidisciplinary LVS referral. The majority of the professionals with the authorization to refer patients (ophthalmologists, low vision optometrists in consultation with ophthalmologists) said that, in line with shared decision making, they only refer patients if they want to be referred and that a great amount of patients with whom they discuss multidisciplinary LVS and offer a referral to do not want to because of various reasons.

> *"It goes pretty fast, people know whether they want it or not. But there is a really large group that doesn't want it (...) I think half of the patients say 'I'm feeling too good' or 'I don't want to'. Maybe even more than half (Ophthalmologist, male, aged 42)."*

TABLE 1. Characteristics of the study population (N=30)

	n (%)	Mean (SD)	Median [range]
Characteristics professionals (n=16)			
Sex, female	6 (40)		
Age (in years)		47 (8.9)	46 [30-64]
Profession			
Ophthalmologist	7 (44)		
LVS professional	9 (37)		
Low vision optometrist	3 (33)		
Professional multidisciplinary LVS organizations	6 (67)		
Optometrist	1 (17)		
Eligibility assessor/administrator	2 (33)		
Clinical physicist	1 (17)		
Advisory professional	1 (17)		
Manager	1 (17)		
Years of work experience		15.5 (10.2)	15 [0.5-35]
Characteristics patients (n=14)			
Sex, female	10 (70)		
Age (in years)		74 (11.6)	74.5 [55-96]
Visual impairment			
Mild VI[a]	3 (21)		
Moderate VI[a]	8 (57)		
Severe VI[a]	1 (7)		
Monocular vision	1 (7)		
Reduced vision and visual field Defect	1 (7)		
Eye disease[b]			
Macular degeneration	9 (64)		
Glaucoma	3 (21)		
Diabetic retinopathy	3 (21)		
Cataract	1 (7)		
Years since diagnosis		10 (13.1)	5 [0.3-44]
Years since referral		2 (1.8)	0.75 [0.2-6]

Abbreviations: SD, standard deviation; VI, visual impairment
[a]According to Word Health Organization (WHO) criteria
[b]Patients could have had more than one eye disease

TABLE 2. Barriers and facilitators in the referral pathways to low vision services from the perspective of professionals and patients

Level	Barriers/Facilitators	Professionals	Patients
Individual level	Motivation	+, –	+
	Self-advocacy	+, –	+
	Experienced impact of the VI	+, –	+
	Participation needs	+, –	+
	Attitude regarding asking for help and seeking healthcare	–	
	Disease duration	+, –	
	Lack of awareness and knowledge of LVS	–	
	Acceptance of the VI	+, –	–
	Other individual factors (Cultural background, unawareness of the eye disease, overall health condition and other private circumstances)	–	
Interpersonal level	Information provision LVS	+, –	+, –
	Communication skills/strategies healthcare professionals	+	+, –
	Social support	+, –	+
	Length of patient-provider relationship	+, –	+
	Other sources of LVS information	+	+
Organizational level	Communication between health professionals	–	
	Cooperation between providers	+	
	Care coordination	–	
	Low vision optometric services	+	
	Time constraints ophthalmic practice	–	–
Community level	Fear of stigma	–	
	Distance to LVS/Transportation	–	+, –
	Education of healthcare providers of LVS	+	
Public policy level	Dutch healthcare system	+, –	+
	Regional service provision	+	
	Long waiting lists	–	

Abbreviations: LVS, low vision services; VI, visual impairment. (+) facilitator, (-) barrier

Some patients mentioned that one of the main reasons to be referred was that they were open to it, willing to get help, curious about what multidisciplinary LVS would bring them or trusted the advice of their ophthalmologist.

> "*I thought it was good, I think every little bit helps, so if [name multidisciplinary LVS organization] can help me with this, for example with glasses or something, I think it's great (Male, aged 96, macular degeneration).*"

Self-advocacy

Both professionals and patients mentioned self-advocacy to be an important facilitator. According to half of the professionals, patients who are able to express their experienced impairments in daily life, who actively ask for possibilities to enhance their visual functioning, or who actively ask for a referral, are more likely to be referred:

> *"It also depends on the patients ability to self-advocate. (…) Yes, they are more likely to say that they want something or they are more likely to say to the doctor 'refer me (to multidisciplinary LVS)' or 'this does not work and that does not work anymore' (Optometrist multidisciplinary LVS, female, aged 39)."*

This was confirmed by several patients who mentioned to be referred after actively asking for referral in consultation with their ophthalmologist, sometimes after actively searching for information about multidisciplinary LVS on the internet. In turn, not being an effective self-advocate as a patient was mentioned as a barrier by some professionals.

Experienced impact of the visual impairment

The experienced impact of the visual impairment was mentioned as a facilitator as well as a barrier in the referral pathways to multidisciplinary LVS by participants. Almost all patients stated that the reason for being referred and wanting multidisciplinary LVS was the impact of visual impairment on their daily life, mostly in practical activities such as reading, driving, watching TV and biking, but also fatigue and work.

> *"Yeah, watching TV, especially reading the newspaper, what I always do. Sometimes when I was cooking food, I didn't see it well. Yeah, very simple things actually (Female, aged 72, glaucoma)."*

Several professionals stated that the practical implications of patients' visual impairment are often the reasons for patients to seek multidisciplinary LVS and a starting point for professionals to talk about multidisciplinary LVS during consultation. Several professionals indicated that they actively ask patients about their impairments in daily life activities or patients bring it up themselves. Furthermore, some professionals reported that mental wellbeing can be the reason to suggest a referral, for example in patients whose vision has suddenly deteriorated.

> *"In the beginning you are quite restless, so I wanted to know what you (multidisciplinary LVS) can do for me. That is the reason that I brought it up in a consultation with my ophthalmologist. (…) Yes, it makes you a little anxious, 'What else can I do,*

can I still help myself'? You feel you are becoming less independent, you have to ask for help (Female, aged 88, macular degeneration)."

Participation needs

Several professionals thought that participation needs of patients are key in the patients' motivation for referral. According to these professionals, how actively or in-actively patients participate in life and how important that is for them, determines if they are open to multidisciplinary LVS and open to accept a referral. Some patients may not have participation needs anymore, possibly because they sometimes say they are 'too old', reflecting they have found resignation in the fact that they are not able to do certain things anymore.

"*While the one does not have that need and says 'I am happy that I am still able to see the television and I walk a little bit outside and all that goes well', someone else may want to drive their car or has to take care of someone and then says 'I really need to be able to ride my bike' (Ophthalmologist, male, aged 42).*"

For some patients the wish to continue their participation in society, for example to be able to work (again), to participate in activities that are important to them or to participate socially stimulated their referral.

"*I thought 'The fact that I will see less won't bring me down' (...), so I thought I need to make sure that I can keep reading and talk on the phone with people, internet, e-mail, using the mobile phone with the library on it and the reading function. So basically, to be able to do these activities, to stay active as much as possible (Male, aged 78, macular degeneration).*"

Attitude regarding asking for help and seeking healthcare

Several professionals stated that patients' attitude regarding asking for help and seeking healthcare in general sometimes hamper patients' motivation and in turn referral. They indicated that elderly patients are those who often refuse multidisciplinary LVS, because of generationally typical opinions. Some believed that patients who were born before 1950 and experienced the war prefer not to ask for help.

"*A whole generation of people simply has learned to take care of themselves and not to ask for help, while I think the current generation is better able to do that than people who are aged 70 or older (LVS professional, male, aged 56).*"

Disease duration

From the professionals' point of view, disease duration may influence the patients' motivation for multidisciplinary LVS and thus, referral. Some professionals stated that patients with a newly diagnosed eye disease, especially neovascular macular degeneration, often do not want to be referred to multidisciplinary LVS right away, because they hope that the treatment (e.g., anti-VEGF injections) will improve their vision and therefore want to await the treatment effect. In the early stages, some patients first need to find out what it means to have a visual impairment and are already helped with simple advice.

> *" (...) Especially with recently diagnosed macular degeneration, people do not really want that yet. Because they are still in the beginning of that treatment and they want to see better again and they still have hope that it will all get better (Ophthalmologist, female, aged 43)."*

Lack of awareness and knowledge of LVS

Lack of awareness and knowledge of multidisciplinary LVS was mentioned by professionals as another barrier in the referral pathways to multidisciplinary LVS. Some professionals explained that patients are often unaware of the available services and are dependent on the healthcare professionals to inform them. Patients also do not always remember what is being said about multidisciplinary LVS during a consultation, as they may be overwhelmed by the information given, which may lead to unawareness and, in turn, to a barrier to multidisciplinary LVS access:

> *"When you have a consultation with a patient, they remember 25% when leaving and 10% when they are at home. So a lot (of information) is lost. So you shouldn't be surprised when people don't remember that you've talked about it (multidisciplinary LVS) (Ophthalmologist, male, aged 64)."*

In addition, several professionals believed that the reasons for some patients to not wanting multidisciplinary LVS and refusing referral might be related to not knowing what to expect from a multidisciplinary LVS.

Acceptance of the visual impairment

Both professionals and patients indicated that acceptance of the visual impairment can play a facilitating or hindering role in the referral process. Professionals indicated that some patients go through a complicated grieving process or have difficulties to adapt and think as vision loss as a temporary problem. Some patients stated that they have been informed about multidisciplinary LVS before, but refused it because they felt not ready for it at that moment, because it would symbolize actually being visually impaired.

> *"I walked in there once, during a walk-in consultation hour and that was very confronting for me. I was welcomed by a woman who was blind and she showed me around in a room and showed me all the LVAs they had. (…) Yeah, then you are confronted with the fact 'I need something, I'm welcomed by a blind woman, so it could get even worse, for me it could also go that way' (Male, aged 60, macular degeneration and glaucoma)."*

Several professionals stated that problems with acceptance of the visual impairment can be a reason to discuss multidisciplinary LVS with patients.

> *"Yeah, those are often the people who had acute vision loss. Because of a trauma or vascular occlusion or something like that and indeed for those people acceptance is often difficult and it takes time. Then I also often talk about LVS and that they can help with that (Ophthalmologist, female, aged 43)."*

Other individual factors

Some professionals specialized in diabetic retinopathy thought that cultural background within this patient group may also hamper multidisciplinary LVS referral. It was mentioned that for some patients it is more common to fully rely on the competences of the medical doctor, and they may lack awareness of the positive impact their own actions can have on their disease outcome.

Another factor that was indicated as a barrier by several professionals was patients noticing late that they have problems with their eye sight. Especially in glaucoma, patients are sometimes unaware of their (severity of) visual field defects due to compensatory strategies and habituation to the impairment, resulting in late diagnosis by the ophthalmologist and late referral to multidisciplinary LVS. Besides that, patients with glaucoma may still have a quite good visual acuity and ophthalmologists therefore might not think about referring.

The overall health condition of patients and/or other private circumstances were also mentioned to be a barrier in patients' access by some professionals. Professionals mentioned that patients who have a bad overall health condition, e.g., serious illness or cognitive impairment, are those who drop out after referral, who refuse referral or who are not referred in the first place.

Interpersonal level

Information provision multidisciplinary LVS

Information provision came forward as a facilitator as well as a barrier from both the professionals' and patients' perspectives. Half of the patients reported that they have not been informed by their provider about multidisciplinary LVS or to have initiated their

referral. In contrast, almost all ophthalmologists and low vision optometrists (those with the authorization to refer patients) reported to regularly inform patients about multidisciplinary LVS. Several professionals reported to regularly hear from patients that they wished they had been informed and referred earlier, immediately at the time of diagnosis or shortly after. Although the wish for earlier information provision was also stated by several patients, most patients felt that they were referred at the right time in due course, often as a result of self-advocacy.

> *"If the diagnosis is determined, they should give you options. The ophthalmologist could have told me first 'We will first await the treatment effect and then we will see if we can possibly refer you to the multidisciplinary LVS organization', or something like that. That would have been much better. It would also have given me more peace of mind if someone would have said that (Female, aged 55, macular degeneration)."*

Patients who have a check-up appointment with their ophthalmologist only once in a while (e.g., every 6 months to every year) are at risk of not being informed, according to some professionals. Besides that, professionals mentioned that ophthalmologists may not pay attention to potential multidisciplinary LVS needs of patients during every consult, because of prioritizing the medical aspect of the disease within the time constraints of consultation. In addition, ophthalmologists might not report about informing their patients, because of unclear assumptions about what LVS has to offer. For example, in young patients referrers may assume that patients are too young to have multidisciplinary LVS needs, whereas in older patients they may assume that patients are too old to benefit from multidisciplinary LVS. Another reason mentioned by several professionals was that ophthalmologists may predominantly use the visual acuity criterion of >0.5 logMAR, despite the before mentioned possibilities for broader interpretation of the guideline.

In addition, several professionals stated that many patients with visual impairment have near vision impairment as well, which is not measured in the ophthalmic practice/ hospitals. As a consequence, ophthalmologists may forget to refer these patients, as they relate to distance visual acuity when referring, although these patients might benefit from multidisciplinary LVS too:

> *"(...) People with wet macular degeneration who receive injections, the distance vision is often good enough and they cannot read anyway, but often we do notice that the reading acuity is bad. That group is also often overlooked and therefore not referred because of their distance vision not being bad enough. (LVS professional, female, aged 45)."*

Communication skills/strategies healthcare professionals

Communication skills and strategies of professionals in eye care were identified as facilitators and barriers from both perspectives. Several professionals reported to use different communication skills when discussing multidisciplinary LVS. Listening, probing questions about daily life activities and showing empathy were mentioned to be important to investigate patients' multidisciplinary LVS needs.

> "*I use my assessment and my communication skills to point that out, (…) a bit of sensing what people can and cannot do and whether they live alone or whether there is help, how the groceries are going, whether they need help with that, things like that (…). Well, reading, how that goes, watching TV, mobility, I think those are the most important three to always ask (Low vision optometrist, female, aged 45).*"

Some of these communication skills were also mentioned by patients to be important to investigate multidisciplinary LVS needs or were the reason for them to think positively about LVS, for example being asked questions about daily life activities and being treated respectfully.

> "*They take the time for you. That is important, the main thing is that you are a person and that people see that. (…) At the LVS that man asked me 'When you look at me, what parts do you see of my face?' And I started laughing (…) and I said 'No one had ever asked me such a specific question' (Male, aged 60, glaucoma and macular degeneration).*"

According to one patient, lacking communication skills hindered referral as there is less openness to discuss patients' multidisciplinary LVS needs:

> "*(…) I have experience with two doctors. I think both doctors are very capable, with one doctor I talk very easily and he listens and the other ophthalmologist stays focused on the screen and it is much more difficult to have conversations with him. Then it is much more difficult to get it started (Female, aged 88, macular degeneration).*"

Both professionals and patients identified referral facilitators related to communication, including sensing the right moment to talk about LVS and repeating multidisciplinary LVS information over time as patients might not be ready at first. In addition, managing expectations of patients about the disease prognosis and about possible future multidisciplinary LVS needs was mentioned as another facilitator. Some professionals noted the need to motivate and encourage patients if they are hesitant about the referral

by using clear examples of multidisciplinary LVS possibilities and to illustrate why it may be useful and what to expect. This may reduce fears and may create readiness.

Social support

Half of the professionals stated that family or significant others play an important role during consultations. Family and significant others help to identify and specify patients' multidisciplinary LVS needs when patients find it difficult to express their needs.

> *"And it also depends on the people that accompany patients. Sometimes there are children who are very active and who want everything to be done (for their parent). But when there is no company, or a neighbor or something like that, then of course the connection is much weaker and then they don't care what is done. So if the patients' company is stimulating, then it is of course much better (Ophthalmologist, female, aged 43)."*

Some patients said that family facilitated their multidisciplinary LVS entry, by contacting and helping them register at the LVS and arranging the initial appointment. Furthermore, some professionals and patients stated that patients may be informed by friends, neighbors or peers, which can in turn initiate multidisciplinary LVS referral.

Length of patient-provider relationship

The length of the patient-provider relationship was mentioned to be both a barrier and facilitator, where short patient-provider relationships may hamper access to multidisciplinary LVS, long term relationships were a facilitator. Some of the professionals working in non-academic hospitals reported having long patient-provider relationships with patients with chronic eye disease, as they see them regularly for check-up appointments. Consequently, this facilitates the opportunity to talk about multidisciplinary LVS. Some patients also mentioned a long patient-provider relationship to stimulate multidisciplinary LVS access, because of trust and openness to talk about multidisciplinary LVS needs.

> *"Yeah, I've been treated there regularly, so of course, I've known him (rehabilitation physician) for years. To him I dared to say 'Can't you refer me there?' (Female, aged 74, macular degeneration)."*

Other sources of LVS information

Patients may be informed by patient associations or other healthcare professionals (e.g., nurse, ophthalmic assistant) about multidisciplinary LVS. Access to the internet as well as patient resources were identified as sources of information by professionals and patients.

These may stimulate patients to contact multidisciplinary LVS themselves or discuss it with their medical specialist.

Organizational level

Communication between health professionals

A lack of communication between health professionals was mentioned to be a barrier for referral by some professionals. For example, ophthalmic assistants who talk with patients about their multidisciplinary LVS needs, but subsequently forget to pass on this information to the ophthalmologists. Furthermore, some professionals mentioned not receiving communication or feedback from the multidisciplinary LVS about their referral and patient outcomes, as this communication would provide relevant information about the effect, which they in turn could use to inform patients and would help to enhance awareness.

> *"Then you get feedback about what you can do for the patient and I think if I would get more feedback about the patients I referred (...) then I think that the next referral is a bit more active because I can also include that in the conversation with the next patient who may be in doubt (Ophthalmologist, female, aged 47)."*

Cooperation between providers

Some professionals reported that investing in good and long collaboration between the different healthcare providers involved in the delivery of multidisciplinary LVS promotes referral. This ongoing relationship generates efficient lines of communication, stimulates trust between professionals and facilitates referral pathways.

Care coordination

Lack of coordinated care was mentioned to be another barrier in the access by some professionals. They reported that especially in treatment with anti-VEGF injections, patients tend to see different professionals for their treatment whereas no one takes responsibility for potential needs that could be met by multidisciplinary LVS.

> *"That are the people who, if you don't watch out, are being overlooked and therefore are not referred, because both patient and doctor are busy with saving what can be saved (regarding eyesight) and then sometimes they forget that in the meantime help is also needed at another level. Especially because this group doesn't often see their own ophthalmologist, as one day this person performs the injection and tomorrow that person, and so on (Ophthalmologist, male, aged 64)."*

In addition, some professionals said that it is not always recorded when multidisciplinary LVS is discussed with a patient. Ophthalmologists may not know whether patients were referred or may forget to come back to it at a later stage.

Low vision optometric service

According to several professionals, the presence of a low vision optometric service at hospital ophthalmology departments facilitate multidisciplinary LVS referral. Ophthalmologists sometimes may prefer to first refer to the optometrist for optical LVAs (which may be an outpatient service as well) instead of referring directly to an outpatient multidisciplinary LVS. According to some professionals, a low vision optometric service may also break down barriers for some patients to make use of multidisciplinary LVS.

Optimizing remaining vision with optical LVAs is the main reason for patients to first go to the optometric service, before considering multidisciplinary LVS, according to some professionals. Low vision optometrists have an important signaling function and may also refer to multidisciplinary LVS.

In some Dutch hospitals a delegation arrangement between ophthalmologists and optometrists is introduced, whereby optometrists are authorized to refer patients as well as ophthalmologists. With this arrangement, optometrists do not have to consult the ophthalmologists before referring a patient. According to some professionals, this facilitates referral as it saves time for ophthalmologists and speeds up the delivery to multidisciplinary LVS.

Time constraints ophthalmic practice

According to some professionals and patients, lack of time in the ophthalmic practice forms a barrier in patients' referral and leads to limited information provision:

> *"I also think that we could refer more, but we somehow don't do that, also because of the busy consultation hours (…) (Ophthalmologist, female, aged 43)."*

Community level

Fear of stigma

Some professionals reported that fear of stigma can be a reason for some patients to refuse multidisciplinary LVS, e.g., LVAs. The fear of being stereotyped and being ashamed of using LVAs may hinder their referral.

> *"Then it has a stigmatizing effect and then people say 'I am not ready for that yet'. I always compare it with my parents who didn't want to walk with a walker after hip rehabilitation. Then everybody would have seen that they had something. (Ophthalmologist, male, aged 42)."*

Distance to LVS/Transportation

Distance to multidisciplinary LVS and problems with transportation was identified as another barrier by several professionals. Examples that were mentioned are people living remotely (e.g., on an island), elderly patients who are dependent on others and patients not wanting to be a burden for their family regarding transportation to the multidisciplinary LVS. Some patients said that distance to multidisciplinary LVS and transportation possibilities are aspects they considered for LVS utilization. However, all patients reported not to have problems with distance or transportation, because they either lived close to a multidisciplinary LVS, had family who could bring them, or received taxi support by their health insurance.

Education of healthcare providers of LVS

Some professionals stated that education about LVS for eye care professionals involved in the delivery of multidisciplinary LVS is important to create awareness, which in turn facilitates referral.

> "*Ophthalmologists have relatively little time, so we try to make the ophthalmologists, the optometrists, the technical ophthalmic assistants (…) as aware as possible about our work (LVS professional, female, aged 45).*"

Public policy level

Dutch healthcare system

From both the patients' and the professionals' perspective the Dutch healthcare system hampers and promotes multidisciplinary LVS access. As multidisciplinary LVS are paid by health insurance in the Dutch healthcare system, there were no patients who experienced a barrier in the access due to costs.

> "*I also have a reasonable pension, so we can manage just fine financially. (…) It (care of multidisciplinary LVS organization) is still 100% reimbursed. (…) I have visual problems and my own compulsory deductible goes to that (Male, aged 78, macular degeneration).*"

However, according to one professional the compulsory deductible payment within the Dutch health insurance can be a barrier for some patients to purchase LVAs. However, another professional mentioned that older patients often have comorbid diseases. For those patients, the compulsory deductible payment is often already paid for other medical care and therefore does not form a barrier. Moreover, according to one professional, restructuring of the Dutch healthcare system has increasingly led to shorter patient-provider relationships, which may be a reason why some patients with multidisciplinary LVS needs may not be referred.

Regional service provision

Some professionals reported the regional provision of LVS in the Netherlands to be a facilitator in the access towards multidisciplinary LVS as almost every potential patient can find help in their own living area.

Long waiting lists

According to some professionals, long waiting lists for multidisciplinary LVS organizations form a barrier in the referral pathways. These occur as a result of staff shortages at the multidisciplinary LVS organizations, which leads to long waiting lists. As a consequence, some patients drop out after referral.

DISCUSSION

Our study aimed to explore barriers and facilitators in the referral pathways to multidisciplinary LVS of adults aged 50 or older in the Netherlands from both the professionals' and patients' perspective. We identified various barriers and facilitators on individual, interpersonal, organizational, community and public policy level, which highlights the complex interplay of factors influencing the referral pathways to multidisciplinary LVS. Our findings indicate that patients' motivation for multidisciplinary LVS, influenced by factors such as perceived impact of the visual impairment, participation needs and attitudes, plays a significant role in the referral to multidisciplinary LVS. At the same time, patients' referral seems to be highly depended on adequate information provision about multidisciplinary LVS and communication skills of professionals. Possessing self-advocacy skills and having a social support network as a patient seems to be an important facilitator as well.

Our results show that patients' multidisciplinary LVS referral and utilization seem to be dependent on a patients' intrinsic motivation for multidisciplinary LVS. Professionals reported only referring patients who indicated that they want to be referred. Several factors identified in this study seem to function as a barrier or facilitator for patients' motivation. They comprise (lack of) acceptance of the visual impairment, disease duration, lack of knowledge about multidisciplinary LVS and attitudes of patients. In addition, we found that (not) having clear participation needs of patients seem to hinder or facilitate patients' multidisciplinary LVS motivation and thus referral. Eye care professionals should be aware however that not having participation needs may be related to patients not having a clear perception of the possibilities that multidisciplinary LVS has to offer to improve quality of life. Vision-specific patient reported outcome measures (PROMs) may help professionals to identify factors related to patient motivation to guide their referral procedures.[48,49]

Our results indicate that patients who have self-advocacy skills are more likely to be referred, as they are more likely to discuss their multidisciplinary LVS needs with their provider or contact multidisciplinary LVS themselves. This corresponds with previous literature on LVS delivery[25,50] and implies that patients in need of LVS, but who lack self-advocacy skills are especially at risk of not being referred to LVS. Research in other patient populations suggests that self-advocacy is a teachable skill that contributes to an individualized care trajectory that fits patients' needs, preferences and values.[51,52] Furthermore, communication aids for patients in medical consultations, for example Question Prompt Lists, may help patients to express their needs and enhance patient participation and information provision.[53]

We found that information provision by eye care providers influences multidisciplinary LVS referral, and has also been reported by others.[31,54,55] There seems to be a discrepancy between the professionals' and patients' experiences. Whereas almost all ophthalmologists in this study seemed to regularly inform patients about multidisciplinary LVS and to refer them, some patients reported to have been informed late or elsewhere.

Ophthalmologists' lack of attention towards possible multidisciplinary LVS needs, inadequate assumptions about certain subgroups not having needs (e.g., younger age groups), and lack of time were identified as important barriers. Previous literature reported delayed referral as a result of lacking information provision, which was not confirmed by our study, as most patients felt that they self-advocated or had been referred at the right time. Furthermore, improvement of procedures may be facilitated by tools, for example, electronic health record-based clinical decision support systems to stimulate timely referral and to help diminish inadequate assumptions about whom to refer.[56]

The communication skills and strategy of providers seem to be important in the referral pathways as well. Lack of effective communication has been reported before as a barrier to LVS.[54] Our study showed specific communication skills that facilitate referral, such as sensing and timing the right moment to talk about multidisciplinary LVS to patients, actively asking patients questions about daily life functioning, using clear examples, motivating patients, managing expectations and repeating information are facilitating communication strategies for discussing patients' multidisciplinary LVS needs and referral. These skills and strategies are in line with effective patient-provider communication and a patient-centered approach[57,58] which may lead to increased access to care.

Social support networks of patients seemed to be a relevant facilitator as well, which is in accordance with previous work.[22] Family and other significant others present during consultations with the ophthalmologist or low vision optometrist seemed to increase needs identification. Furthermore, social support facilitated access to multidisciplinary LVS. This implies that professionals should encourage patients to take a trusted person to consultations.

Strengths and limitations

A strength of this study is the inclusion of both the patients' and the professionals' perspectives. We thereby triangulated[59] our findings, which we believe contributed to a more comprehensive understanding of factors influencing the referral pathways to LVS. Moreover, by means of member checking we established credibility. In addition, we tried to include a heterogeneous population of professionals and patients, which enhanced transferability of our results. Furthermore, we nearly met our approximated sample size per subgroup, which was found to be sufficient in terms of information power[41] during the research process for the exploratory aim of the study.

Despite our efforts, a limitation of our study is that we were only able to include patients who followed up on the referral. As a consequence, the perspective of patients who potentially would have benefited from multidisciplinary LVS, but who remained 'under the radar', for example because they were not offered a referral, refused referral or did not have access due to other barriers in the referral pathway, are missing. Nonetheless,

we were able to shed some light on this patient group and their related barriers and facilitators with the professionals' point of view.

In general, a limitation of interview studies is their retrospective nature. For patients, we tried to mitigate recall bias by inviting patients who were referred to multidisciplinary LVS not longer than 6 months ago. However, it turned out to be difficult to meet this criterion, partly caused by the corona pandemic. The initial protocol was to include patients who were referred within 6 months. Since the corona pandemic made this impossible and our funds were limited, we decided to accept also patients as participants who had been referred between 8 months and 6 years ago. This might have aggravated recall bias.

Lastly, our results relate to multidisciplinary LVS referrals in the Dutch context, which should be taken into account when applying the results to other countries, as referral practices and LVS provision vary internationally.

Conclusion

Our findings imply that providers' lack of information provision, especially to patients who lack self-advocacy skills, hamper referral to multidisciplinary LVS. At the same time, in the Dutch context, not all patients who are potentially eligible for LVS seem to want to be referred and to have rehabilitation needs. Providers should have attention for patients' multidisciplinary LVS needs and actively inform them and their social network about multidisciplinary LVS to facilitate access. Educating and training providers about how and when to address multidisciplinary LVS may help to reduce barriers in the referral pathways. In addition, referral procedures may benefit from tools that make providers more aware of multidisciplinary LVS, e.g., referral alert tools or PROMs. The results of this study may provide eye care professionals and policy makers with insights to mitigate barriers in multidisciplinary LVS referral procedures and to organize them more efficiently. This in turn will help to facilitate timely referral of patients who qualify, and who are ready for multidisciplinary LVS to help them to enhance their quality of life.

REFERENCES

1. Kempen GI, Ballemans J, Ranchor AV, van Rens GH, Zijlstra GA. 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. *Qual Life Res.* 2012;21(8):1405-11.
2. Lamoureux EL, Fenwick E, Moore K, Klaic M, Borschmann K, Hill K. Impact of the severity of distance and near-vision impairment on depression and vision-specific quality of life in older people living in residential care. *Invest Ophth Vis Sci.* 2009;50(9):4103-9.
3. Rees G, Fenwick EK, Keeffe JE, Mellor D, Lamoureux EL. Detection of depression in patients with low vision. *Optom Vis Sci.* 2009;86(12):1328-36.
4. van der Aa HPA, Comijs HC, Penninx BWJH, van Rens GHMB, van Nispen RMA. Major Depressive and Anxiety Disorders in Visually Impaired Older Adults. *Invest Ophthalmol Vis Sci* 2015;56(2):849-54.
5. Schakel W, Bode C, van de Ven PM, van der Aa HPA, Hulshof CTJ, van Rens GHMB, van Nispen RMA. Understanding fatigue in adults with visual impairment: A path analysis study of sociodemographic, psychological and health-related factors. *PLOS ONE.* 2019;14(10):e0224340.
6. Hong T, Mitchell P, Burlutsky G, Samarawickrama C, Wang JJ. Visual impairment and the incidence of falls and fractures among older people: longitudinal findings from the Blue Mountains Eye Study. *Invest Ophthalmol Vis Sci.* 2014;55(11):7589-93.
7. World Health Organisation. 9D90 Vision impairment including blindness. 2022. In: International statistical classification of diseases 11th Revision [Internet]. [cited 2022 Nov 11]. Available from: https://icd.who.int/browse/2024-01/mms/en#1103667651.
8. Bourne R, Steinmetz JD, Flaxman S, Briant PS, Taylor HR, Resnikoff S, et al. Trends in prevalence of blindness and distance and near vision impairment over 30 years: an analysis for the Global Burden of Disease Study. *Lancet Glob Health.* 2021;9(2):e130-e43.
9. Owsley C, McGwin G, Jr, Lee PP, Wasserman N, Searcey K. Characteristics of Low-Vision Rehabilitation Services in the United States. *Arch Ophthalmol* 2009;127(5):681-9.
10. Luu W, Kalloniatis M, Bartley E, Tu M, Dillon L, Zangerl B, Ly A. A holistic model of low vision care for improving vision-related quality of life. *Clin Exp Optom.* 2020;103(6):733-41.
11. Markowitz SN. Principles of modern low vision rehabilitation. *Can J Ophthalmol.* 2006;41(3):289-312.
12. Lim YE, Vukicevic M, Koklanis K, Boyle J. Low Vision Services in the Asia-Pacific Region: Models of Low Vision Service Delivery and Barriers to Access. *J Vis Impair Blind.* 2014;108(4):311-22.
13. van Nispen RMA, Virgili G, Hoeben M, Langelaan M, Klevering J, Keunen JEE, van Rens G. Low vision rehabilitation for better quality of life in visually impaired adults. *Cochrane Database Syst Rev.* 2020(1).
14. American Optometric Association. Clinical Practice Guidelines n.d. [cited 2022 Nov 8]. Available from: https://www.aoa.org/practice/clinical-guidelines/clinical-practice-guidelines?sso=y.
15. Sinclair A, Ryan B. Low vision: The essential guide for ophthalmologists: The Guide Dogs for the Blind Association; 2021 [cited 2022 Nov 8]. Available from: https://www.rcophth.ac.uk/resources-listing/low-vision-the-essential-guide-for-ophthalmologists/.
16. Low Vision Academy. Guidelines for the visual rehabilitation of the visually impaired 2016 [cited 2022 Nov 8]. Available from: https://en.lowvisionacademy.org/2014/09/16/guidelines-for-the-visual-rehabilitation/.

17. Nederlands Oogheelkundig Gezelschap. Visuele beperkingen - verwijzing en revalidatie [Vision disorders: referral and rehabilitation] 2020 [cited 2022 Jan 8]. Available from: https://richtlijnendatabase.nl/richtlijn/visuele_beperkingen_-_verwijzing_en_revalidatie/verwijzing_voor_revalidatie_bij_visuele_beperkingen.html.
18. Pollard TL, Simpson JA, Lamoureux EL, Keeffe JE. Barriers to accessing low vision services. *Ophthalmic Physiol Opt.* 2003;23(4):321-7.
19. Khan SA, Shamanna B, Nuthethi R. Perceived barriers to the provision of low vision services among ophthalmologists in India. *Indian J Ophthalmol.* 2005;53(1):69-75.
20. Overbury O, Wittich W. Barriers to low vision rehabilitation: the Montreal Barriers Study. *Invest Ophthalmol Vis Sci.* 2011;52(12):8933-8.
21. Stolwijk ML, van Nispen RMA, Verburg IWM, van Gerwen L, van de Brug T, van Rens GHMB. Trends in low vision service utilisation: A retrospective study based on general population healthcare claims. *Ophthalmic Physiol Opt.* 2022;42:828–38.
22. Lam N, Leat SJ. Reprint of: Barriers to accessing low-vision care: the patient's perspective. *Can J Ophthalmol.* 2015;50 Suppl 1:S34-9.
23. Lam N, Leat SJ, Leung A. Low-vision service provision by optometrists: a Canadian nationwide survey. *Optom Vis Sci.* 2015;92(3):365-74.
24. Kaleem MA, West SK, Im L, Swenor BK. Referral to Low Vision Services for Glaucoma Patients: Referral Criteria and Barriers. *J Glaucoma.* 2018;27(7):653-5.
25. Kaldenberg J. Low vision rehabilitation services: Perceived barriers and facilitators to access for older adults with visual impairment. *Br J Occup Ther.* 2019;82:466-74.
26. Kaleem MA, West SK, Im LT, Swenor BK. Referral to Low Vision Services for Glaucoma Patients: Referral Patterns and Characteristics of Those Who Refer. *J Glaucoma.* 2017;26(2):e115-e20.
27. Kumar H, Monira S, Rao A. Causes of Missed Referrals to Low-Vision Rehabilitation Services: Causes in a Tertiary Eye Care Setting. *Semin Ophthalmol.* 2016;31(5):452-8.
28. Goldstein JE, Guo X, Boland MV, Swenor BK. Low Vision Care - Out of Site. Out of Mind. *Ophthalmic Epidemiol.* 2020:1-7.
29. Sivakumar P, Vedachalam R, Kannusamy V, Odayappan A, Venkatesh R, Dhoble P, et al. Barriers in utilisation of low vision assistive products. *Eye.* 2020;34(2):344-51.
30. Matti AI, Pesudovs K, Daly A, Brown M, Chen CS. Access to low-vision rehabilitation services: barriers and enablers. *Clin Exp Optom.* 2011;94(2):181-6.
31. O'Connor PM, Mu LC, Keeffe JE. Access and utilization of a new low-vision rehabilitation service. *Clin Exp Optom.* 2008;36(6):547-52.
32. Khimani KS, Battle CR, Malaya L, Zaidi A, Schmitz-Brown M, Tzeng H-M, Gupta PK. Barriers to Low-Vision Rehabilitation Services for Visually Impaired Patients in a Multidisciplinary Ophthalmology Outpatient Practice. *J Ophthalmol.* 2021;2021:1-7.
33. Sarika G, Venugopal D, Sailaja MVS, Evangeline S, Krishna Kumar R. Barriers and enablers to low vision care services in a tertiary eye care hospital: A mixed method study. *Indian J Ophthalmol.* 2019;67(4):536-40.
34. Oviedo-Cáceres MdP, Arias-Valencia S, Hernández-Quirama A, Ruiz-Rodríguez M, Guisasola-Valencia L. Intersectionality and access to visual rehabilitation services: Experiences of people with low vision, a qualitative study. *Br J Vis Impair.* 2022;41(4):831-42.
35. Kyeremeh S, Mashige KP. Availability of low vision services and barriers to their provision and uptake in Ghana: practitioners' perspectives. *Afr Health Sci.* 2021;21(2):896-903.
36. Flaxman SR, Bourne RRA, Resnikoff S, Ackland P, Braithwaite T, Cicinelli MV, et al. Global causes of blindness and distance vision impairment 1990-2020: a systematic review and meta-analysis. *Lancet Glob Health.* 2017;5(12):e1221-e34.

37. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19(6):349-57.
38. Kroneman M, Boerma W, van den Berg M, Groenewegen P, de Jong J, van Ginneken E. Netherlands: Health System Review. *Health Syst Transit.* 2016;18(2):1-240.
39. Green J, Thorogood N. Qualitative methods for health research. 4 ed: sage; 2018.
40. Vasileiou K, Barnett J, Thorpe S, Young T. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Med Res Methodol.* 2018;18(1):148.
41. Malterud K, Siersma VD, Guassora AD. Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qual Health Res.* 2016;26(13):1753-60.
42. McLeroy KR, Bibeau D, Steckler A, Glanz K. An ecological perspective on health promotion programs. *Health Educ Q.* 1988;15(4):351-77.
43. Richard L, Potvin L, Kishchuk N, Prlic H, Green LW. Assessment of the integration of the ecological approach in health promotion programs. *Am J Health Promot.* 1996;10(4):318-28.
44. Birt L, Scott S, Cavers D, Campbell C, Walter F. Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation? *Qual Health Res.* 2016;26(13):1802-11.
45. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess R, editors. In: Analyzing qualitative data: Routledge; 1994. p. 173-94.
46. Parkinson S, Eatough V, Holmes J, Stapley E, Midgley N. Framework analysis: a worked example of a study exploring young people's experiences of depression. *Qual Res Psychol.* 2016;13(2):109-29.
47. Midgley N, Parkinson S, Holmes J, Stapley E, Eatough V, Target M. Beyond a diagnosis: The experience of depression among clinically-referred adolescents. *J Adolesc.* 2015;44:269-79.
48. Rausch-Koster TP, Luijten MAJ, Verbraak FD, van Rens GHMB, van Nispen RMA. Calibration of the Dutch EyeQ to Measure Vision Related Quality of Life in Patients With Exudative Retinal Diseases. *Transl Vis Sci Technol.* 2022;11(4):5.
49. Fenwick EK, Barnard J, Gan A, Loe BS, Khadka J, Pesudovs K, et al. Computerized Adaptive Tests: Efficient and Precise Assessment of the Patient-Centered Impact of Diabetic Retinopathy. *Transl Vis Sci Technol.* 2020;9(7):3-.
50. Burton AE, Gibson JM, Shaw RL. How do older people with sight loss manage their general health? A qualitative study. *Disabil Rehabil.* 2016;38(23):2277-85.
51. Schmidt EK, Faieta J, Tanner K. Scoping Review of Self-Advocacy Education Interventions to Improve Care. *OTJR Occup Particip Health.* 2020;40(1):50-6.
52. Alsbrook KE, Donovan HS, Wesmiller SW, Hagan Thomas T. Oncology Nurses' Role in Promoting Patient Self-Advocacy. *Clin J Oncol Nurs.* 2022;26(3):239-43.
53. Sansoni JE, Grootemaat P, Duncan C. Question Prompt Lists in health consultations: A review. *Patient Educ Couns.* 2015;98(12):1454-64.
54. Southall K, Wittich W. Barriers to Low Vision Rehabilitation: A Qualitative Approach. *J Vis Impair Blind.* 2012;106(5):261-74.
55. Wittich W, Canuto A, Overbury O. Overcoming barriers to low-vision rehabilitation services: improving the continuum of care. *Can J Ophthalmol.* 2013;48(6):463-7.
56. Guo X, Swenor BK, Smith K, Boland MV, Goldstein JE. Developing an Ophthalmology Clinical Decision Support System to Identify Patients for Low Vision Rehabilitation. *Transl Vis Sci Technol.* 2021;10(3):24.

57. Makoul G, van Dulmen S. What Is Effective Doctor–Patient Communication? Review of the Evidence. 2015. In: Clinical Communication in Medicine [Internet]. Hoboken: John Wiley & Sons, [cited 2022 Aug 12]; [30-9]. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1002/9781118728130.ch5.
58. Illingworth R. Patient-Centredness. 2015. In: Clinical Communication in Medicine [Internet]. Hoboken: John Wiley & Sons, [cited 2022 Aug 12]; [40-8]. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1002/9781118728130.ch6.
59. Farmer T, Robinson K, Elliott SJ, Eyles J. Developing and Implementing a Triangulation Protocol for Qualitative Health Research. *Qual Health Res.* 2006;16(3):377-94.

CHAPTER 3

Trends in low vision service utilization: a retrospective study based on general population healthcare claims

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Ophthalmic and Physiological Optics. 2022;42(4):828–38.
doi: 10.1111/opo.12982

ABSTRACT

Purpose

To identify parameters associated with the downward trend in the uptake of multidisciplinary low vision services (LVS) in the Netherlands.

Methods

A retrospective cohort study was conducted based on a Dutch national health insurance claims database (Vektis C.V.) of all adults (≥18 years) who received multidisciplinary LVS from 2015 until 2018. Descriptive statistics were used to assess sociodemographic-, clinical-, contextual characteristics and other healthcare utilization of the study population. With general estimating equations trends in characteristics and healthcare utilization were determined over time.

Results

A total of 49,726 unique patients received multidisciplinary LVS, but between 2015 and 2018, the number of patients decreased by 15%. The majority was aged 65 years or older (53%), female (54%), had a middle (38%) or low (24%) socioeconomic status and lived in urban areas (68%). Between 2015-2018, significant downward trends were found for treatment with intravitreal injections and lens-related diseases for multidisciplinary LVS patients. For physical comorbidity, utilization of ophthalmic care, low vision aids (LVAs) and occupational therapy, a significant upward trend was found over time.

Conclusions

The decrease of Dutch multidisciplinary LVS patients by 15% between 2015 and 2018 might be explained by a reduced distribution of patients treated with intravitreal injections and patients with lens-related diseases within the multidisciplinary LVS. Compared to 2015, patients were more likely to have physical comorbidity, to see an ophthalmologist and to use LVAs and occupational therapy in 2016, 2017 and 2018. This might indicate enhanced access to multidisciplinary LVS when treated by ophthalmologists or within other medical specialties, or the opposite, i.e. less access when not treated within one of these medical specialties. Future research is needed to further examine differences in patterns between multidisciplinary LVS users and non-users.

INTRODUCTION

Worldwide, an estimated 590 million people are currently affected by visual impairment, which is defined as low vision or blindness.[1] Leading causes are uncorrected refractive error, age-related macular degeneration, diabetic retinopathy and glaucoma.[1,2] The majority of the people affected are female and aged 50 or older.[1,3]

A visual impairment can negatively influence quality of life[4] and other areas of health and wellbeing.[5-7] It may affect an individual's orientation and mobility, which increases the risk of falls,[8] the ability to participate in daily life activities and also mental health.[5] It has been repeatedly shown that visual impairment is associated with depression and anxiety.[6,7] In addition, visual impairment has a large societal and economic burden due to increased healthcare utilization as well as low work participation and productivity losses.[9]

Low vision services (LVS) are healthcare services that contribute to quality of life and mental health of people with an irreversible visual impairment by teaching them how to make optimal use of their residual functions, helping them to adapt to visual impairment and to participate fully in society.[10,11] LVS may include, but are not limited to functional assessments, prescription and training in the use of low vision aids (LVAs), occupational therapy, mobility training and mental health treatment. They may be offered by optometrists or multidisciplinary organizations. It has been shown that some of these services, such as prescription of and training in low vision devices, were found to be effective in enhancing quality of life[12] and to be potentially cost-effective from a societal perspective.[13]

Despite the benefits of LVS, over the past decade a discrepancy in the need and the actual uptake of these services has been reported internationally.[11,14] The number of people who utilize LVS seems low compared to the prevalence of people reported to have visual impairment (who should be eligible for LVS). Moreover, in the Netherlands, which has approximately 17 million inhabitants and an estimated 300.000 people with a visual impairment, a downward trend in LVS uptake at multidisciplinary organizations for people with low vision and blindness has been observed in the past few years.[15,16] The benefit of treatment with vascular endothelial growth factor inhibitors (anti-VEGF) for retinal exudative disease, available since 2005, has been suggested as a first important explanation of a decreased need and hence a lower LVS uptake.[17]

Secondly, in 2015 a new healthcare policy was introduced in the Netherlands which led to an instant decrease in LVS uptake which progressed in the years thereafter.[15,16] Sensory disability care was shifted to the Dutch Health Insurance Act (HIA), which meant that patients with a visual impairment now had to pay a compulsory deductible payment for LVS, which has been presumably a barrier for patients to utilize LVS.[15] Both explanations are plausible but need to be studied along with other variables. In addition, data on the extent of the decrease in LVS uptake are lacking, although it may be partially deduced from annual patient numbers of LVS institutions.

Previous international studies have identified several important barriers as well that have explained low uptake of LVS.[18-20] These are related to sociodemographic and clinical patient characteristics, healthcare utilization and contextual characteristics. Examples of patient characteristics are the presence of comorbidity[21] and less severe visual acuity and/or field loss.[20,22]

With regard to barriers related to healthcare utilization, people who have visual impairment may use other types of healthcare instead of LVS, such as optometry[23] or mental healthcare,[24] where their needs may be fully met. Context related barriers that have been reported include lacking referral by eye care professionals,[18] healthcare costs for LVS and lacking service provision due to a widespread LVS patient population and a small distribution or availability of service locations per capita.[19]

Although these study outcomes give valuable insights into which barriers may explain the low uptake, little is known about patterns that could explain the observed downward trend in the Netherlands. In addition, previous studies have mainly been based on qualitative designs, surveys or health records and have been limited by relatively small sample sizes. In recent years, there has been a wide interest in research based on healthcare claims to examine patterns in characteristics and healthcare utilization in patients with various conditions.[25,26] Healthcare claims data are population-based, eligible to be conducted on a large scale and have the advantage of being generalizable. To our knowledge, there is only one study on LVS provision that was based on healthcare claims, in Canada, which described LVS utilization patterns over time from a provider and user perspective.[19] Basilious et al.[19] found that LVS uptake increased over time, but found disparities in the access to these services based on age, sex and geographic location.

The aim of this paper is to describe the national trends between 2015 and 2018 in multidisciplinary LVS utilization in the Netherlands based on healthcare claims and its associations with sociodemographic, clinical and contextual characteristics of multidisciplinary LVS patients, as well as other healthcare utilization of patients using multidisciplinary LVS. The results of this study may provide policy makers with suggestions about how to enhance access to multidisciplinary LVS in line with the global action plan of the World Health Organisation (WHO).[27]

METHODS

Design

We conducted a retrospective study based on a Dutch national health insurance claims database retrieved from Vektis C.V.. We focused on healthcare claims of multidisciplinary LVS patients to examine trends in their characteristics and healthcare utilization.

The Dutch health insurance system

In the Netherlands, curative care is administered by the HIA, which determines that all Dutch citizens are obliged to take out a basic statutory insurance package, including a premium, a compulsory deductible and an income-dependent contribution.[28] The premium and the compulsory deductible are directly paid to the health insurers, the income-dependent contribution is collected by the Dutch tax system. Because of the obligatory basic insurance, almost all (99%) Dutch citizens are covered by health insurance (excluding military personal and convicts). The basic insurance package covers the majority of curative care, including outpatient multidisciplinary LVS, inpatient and outpatient (ophthalmic) medical specialist care, mental healthcare and general medical practitioner care (GP care). Medical aids, such as LVAs, and occupational therapy are partially covered. The average annual premium was 1,158 EUR in 2015 and 1,308 EUR in 2018. The compulsory deductible was 375 EUR in 2015 and 385 EUR as of 2016, which applies to all types of curative care, except for GP care, maternity care, district nursing and dental care (for children <18 years). The income-dependent contribution was 6.95% of income for employees and 4.85% for self-employed persons in 2015, and 6.90% of income for employees and 5.65% for self-employed in 2018.

Moreover, people with low income can receive a monthly contribution towards the healthcare costs up to a maximum of 107 EUR. Besides the basic insurance package, citizens can take out other voluntary supplementary insurance packages, which cover extra costs for services such as dental care, physiotherapy, mental healthcare, occupational therapy and LVAs (e.g., spectacles and lenses). About 85% of all Dutch citizens have at least one additional package.[29]

Healthcare services for all patients and by all healthcare providers, including prescribed medication, are claimed by health insurers, if patients are covered. When citizens receive care within healthcare services, all health professionals administer their delivered care with a corresponding digital code to claim healthcare expenses from health insurers. Next to information about healthcare utilization, claims include data regarding sociodemographic-, clinical- and context related characteristics at the patient level.

Data source

Vektis C.V. continuously collects healthcare claims of all Dutch insurers to give insights about healthcare utilization to the Dutch government, health insurers and care providers.

Demographic-, clinical- and context related characteristics at the patient level are also available.

Study population

Low vision services

Within the HIA, multidisciplinary LVS belongs to sensory disability care. LVS are provided regionally and, as of 2015, are largely funded by health insurance within the basic statutory insurance package. LVS are offered by specialized, for-profit low vision optometrists who mainly prescribe optical aids, and three nonprofit multidisciplinary organizations, that offer the whole range of services supporting individuals to gaining (back) independence and enhance their quality of life. At the multidisciplinary organizations, patients mainly use outpatient LVS, but for some, inpatient LVS is offered, depending on the extent of their needs. The following multidisciplinary LVS are offered: advice in disability assistive products (e.g., computer, smartphone, white cane); support in daily activities; occupational therapy; mobility and orientation training; training in braille reading; psychosocial support and psychological therapy.

According to the Dutch Society of Ophthalmology guideline, 'Vision disorders: rehabilitation and referral' (2011-2020), referral to LVS was advised for people with a decimal visual acuity of <0.3 and/or a visual field of <30° around the central point of fixation and/or an evident request for assistance when therapeutic options in regular ophthalmic practice were not sufficient.[30] For multidisciplinary LVS utilization, patients need to be referred by an ophthalmologist, or in some cases by another medical specialist, e.g., neurologists or geriatricians. Optometrists or general medical practitioners may refer patients to ophthalmologists in the first place. When the visual functioning can be (partially) improved or compensated with optical LVAs, referral to a low vision optometrist should be considered. Therefore, ophthalmologists may refer to low vision optometrists before they refer to multidisciplinary LVS. If the care of the low vision optometrist is not sufficient to meet the patient's needs, the optometrist can refer to multidisciplinary LVS in agreement with the ophthalmologist.

For this study, claims data for the period 1 January 2015 and 31 December 2018 were examined for all visually impaired adults, aged 18 or older, who received multidisciplinary LVS at least once within the HIA at one of the three Dutch multidisciplinary organizations for people with a visual impairment. Inclusion criteria were being insured with the basic statutory insurance package whether or not in combination with voluntary supplementary insurance.

Sociodemographic characteristics

The age and sex of multidisciplinary LVS patients was retrieved from claims data. Socioeconomic status (SES) was retrieved from The Netherlands Institute for Social Research

and was linked to the claims data, based on four-digit postal codes.[31] For information about SES, The Netherlands Institute for Social Research summarizes by factor analysis the average income in a neighborhood, the percentage of people with a low income, low education and those who do not work. Area of residence was operationalized based on four-digit postal codes within claims data, which was linked to information about degree of urbanization of Dutch municipalities from Statistics Netherlands.[32,33] Statistics Netherlands defines five degrees of urbanization based on the density of addresses per square kilometers (km^2): extremely urbanized (2500 addresses or more), strongly urbanized (1500-2500 addresses), moderately urbanized (1000-1500 addresses), hardly urbanized (500-1000) and not urbanized (less than 500 addresses).

For municipalities, the mean density of all addresses per km2 within a municipality compose the degree of urbanization. For this study, degree of urbanization of municipalities was linked to the postal codes within claims data, based on four digits. The five urbanization levels were then aggregated and recoded into the categories rural and urban area of residence, whereby urban area of residence was based on the three highest degrees of urbanization and rural area of residence was based on the two lowest degrees of urbanization.

Clinical characteristics

For clinical characteristics, claims data registered by ophthalmologists were used. Ophthalmic medical specialist care in the Netherlands is offered at general hospitals, university hospitals and independent treatment centers. For reimbursement of medical specialist care, a diagnosis-treatment combination (DTC) is used. It contains information about the total healthcare activities and services that are executed by medical specialists, including information about the medical condition that is treated, type of treatment and type of institution. Ophthalmic medical specialist care includes care provided by ophthalmologists and optometrists. For this study, the claims data of ophthalmologists were collected at the DTC level.

To get information about physical comorbidity, claims data from medical specialist care were used. Data were aggregated at annual level per specialism. Presence of physical comorbidity and the specific comorbidities were examined; the former was defined as having at least one record within one of the corresponding specialisms in a particular year, and the latter as having a record within a certain specialism.

For insights about mental comorbidity, claims data of mental healthcare within the HIA were collected. This comprised basic and specialized mental healthcare, care provided by mental health practice nurses in GP care and other mental healthcare (not specified). Mental healthcare data were aggregated at annual level per type of mental healthcare. Both having mental comorbidity and mental comorbidity at the level of the diagnosis were investigated. Mental comorbidity was defined as having at least one record within

one of the corresponding types of mental healthcare per year. Furthermore, information about mental comorbidity at the level of the diagnosis was retrieved from claims data of specialized mental healthcare, whereby the specific mental comorbidity was defined as having a record of a specific diagnosis in a particular year.

Contextual characteristics

Regarding contextual characteristics, we looked at the types of institutions where patients were treated, which were either hospitals or independent treatment centers. Second, distance to multidisciplinary LVS was investigated with the Google Maps ruler function based on four-digit postal codes and location of the multidisciplinary LVS, assuming that patients would go to the nearest location. Distances were measured in kilometers (km). The ruler function was preferred to the Google Maps route planner, as it was less time consuming and both methods correlated highly (r=0.91).

Other healthcare utilization

To get insight into other healthcare utilization of multidisciplinary LVS patients, claims data of the ophthalmic medical specialist care, GP care, LVAs and occupational therapy were examined.

With regard to ophthalmic medical specialist care, overall utilization of ophthalmic medical specialist care and utilization of intravitreal anti-VEGF injections was investigated at the DTC level. Utilization was operationalized as the number of patients that utilized the healthcare service.

For general practitioner care, LVAs and occupational therapy, claims data were collected and aggregated at an annual level, whereby utilization was defined as having at least one record within one of the corresponding types of healthcare per year.

Statistical analyses

Sociodemographic, clinical and contextual characteristics and other healthcare utilization were expressed as percentages (categorical variables) or mean and standard deviation (continuous variables). For the analysis of trends, we examined associations between time and the different characteristics and other healthcare utilization in multidisciplinary LVS patients. Because multidisciplinary LVS patients could have used multidisciplinary LVS in more than one year, generalized estimating equations (GEE) were used to examine average annual change by calculating regression coefficients and 95% confidence intervals, with 'year' (2015-2018) as independent, categorical variable and the different characteristics and other healthcare utilization in multidisciplinary LVS patients as dependent variables. For the continuous variable 'distance to multidisciplinary LVS', a linear GEE analysis was performed. Other dependent variables were dichotomized, and logistic GEE analyses were performed. An unstructured working correlation structure was assumed to adjust for the

within-subject correlations over subsequent years. The year 2015 was considered as the reference and annual changes in the dependent variables were reported with respect to that year. Effect sizes were reported in percentage points if there were at least two years significantly different from 2015. Since a GEE analysis was performed for each dependent variable separately, a Bonferroni correction for multiple testing was applied by multiplying the p-values by the number of models (21) to control the type I error rate. All the analyses were conducted with the GENMOD procedure in SAS Analytics software version 9.4 (SAS Institute Inc., Cary, NC, USA).

Missing values

There were missing data for some sociodemographic and contextual characteristics at the annual level, specifically for SES, area of residence and distance to multidisciplinary LVS. In all years, missing data were assumed missing completely at random (MCAR) and were <0.4%. In the analysis, we only used complete data.[34]

Ethical approval

The study protocol was reviewed and approved by the Medical Ethics Committee (METC) of the Amsterdam University Medical Centers, location VUmc. The processing of data was in line with the European General Data Protection Regulation (EGDPR) and informed consent was not required. For the use of insurance claims data, permission of the Dutch national insurances was requested and provided. To ensure privacy of individual patients and care providers, data for this study were pseudonymized and aggregated to a minimum subgroup level of n>10.

RESULTS

The analyses included 49,726 unique patients who used multidisciplinary LVS at least once between 2015 and 2018 (Figure 1). Between 2015 and 2018, the number of multidisciplinary LVS patients decreased by 15%, from 19,715 unique patients in 2015 to 16,829 unique patients in 2018.

Trends in sociodemographic characteristics

In the four year period, on average multidisciplinary LVS patients were mainly 65 years or older (53%), female (54%), had a low (24%) or middle SES (38%) and lived in urban areas (68%) (Table 1). The mean age of people entering multidisciplinary LVS services remained stable at 64 years (SD=20) during the whole study period. Compared to 2015, in 2016, 2017 and 2018, the odds of being older than 65 was significantly higher (Table 2). However, the overall increase in the four year period was small with 0.8 percentage points. Although multidisciplinary LVS patients had mainly low or middle SES, were female and lived in urban areas, no significant trends were found with respect to SES, sex and area of residence across the different years.

Trends in clinical characteristics

On average, 66% had physical comorbidity, mainly within the cardiovascular system, sensory nervous system and tumors (Table 1). Furthermore, 13% had mental comorbidity, whereby multidisciplinary LVS patients who utilized specialized mental healthcare (44%) mainly experienced depressive disorders (20%), anxiety disorders (17%), and/or neurocognitive disorders (8%). Most common ophthalmic conditions for which multidisciplinary LVS patients were treated were macular (36%), glaucoma (17%) and lens-related diseases (14%). Compared to 2015, the odds of having physical comorbidity was significantly higher in 2016, 2017 and 2018 (Table 2). Between 2015 and 2018, the relative amount of multidisciplinary LVS patients with physical comorbidity increased with 3 percentage points. Compared to 2015, the odds of having a disease of the lens, macular and diabetic retinal disease was significantly lower in 2018 (and in 2017 for lens diseases). For the other diagnosis groups, no significant trends were found.

Trends in context related characteristics

Of the multidisciplinary LVS patients who went to the ophthalmologist, 17% were treated with intravitreal injections in the four year period and most of them were treated in hospitals (86%) (Table 1). Of all multidisciplinary LVS patients, 77% lived within 20 km from a multidisciplinary LVS. Compared to 2015, the odds of being treated in hospitals by an ophthalmologist versus eye care from an independent treatment center was significantly lower in the years after 2015 (1.8 percentage points; Table 2).

Trends in other healthcare utilization

Between 2015 and 2018, on average GP care was utilized by 78% of multidisciplinary LVS patients, 55% used ophthalmic care, 29% LVAs and 7% used occupational therapy (Table 1). Compared to 2015, the odds of multidisciplinary LVS patients utilizing ophthalmic care was significantly higher in 2016, 2017 and 2018 (9 percentage points; Table 2). For multidisciplinary LVS patients who utilized ophthalmic care, the odds of being treated with intravitreal injections was significantly lower in 2017 and 2018 compared to 2015 (1.7 percentage points). Furthermore, the odds of multidisciplinary LVS patients utilizing occupational therapy (2 percentage points) and LVAs (2 percentage points) was significantly higher in 2016, 2017 and 2018, compared to 2015.

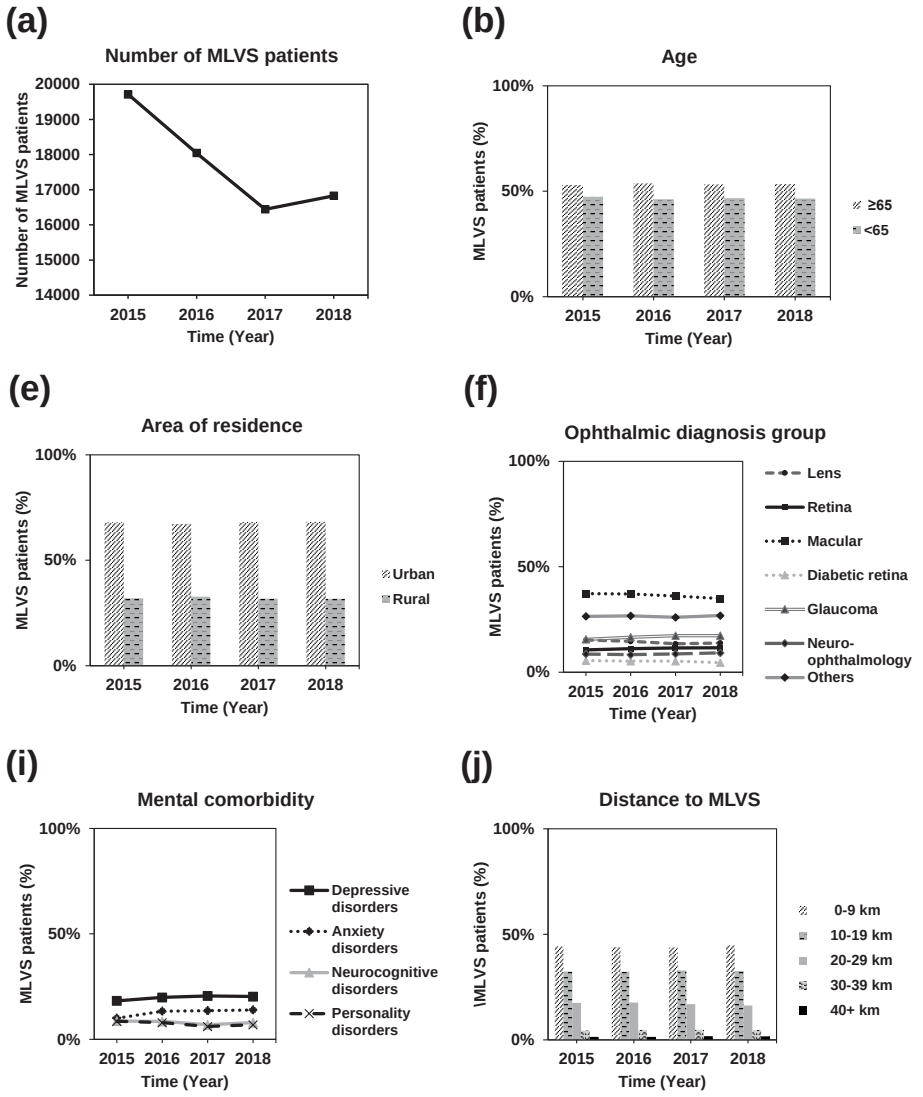
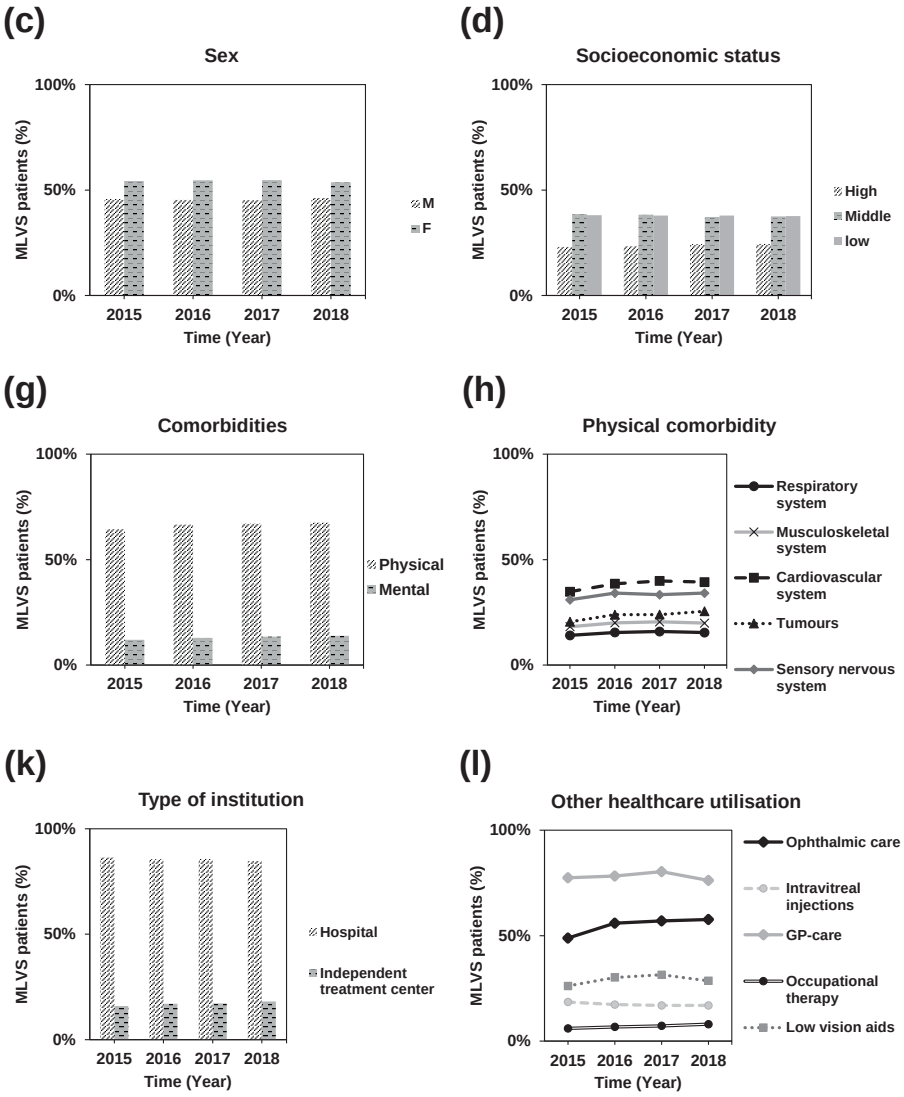


FIGURE 1. Trends in patient characteristics between 2015 and 2018.

Abbreviations: GP care, general practitioner care; MLVS, multidisciplinary low vision services. (a) Number of unique patients per year. *Sociodemographic characteristics:* (b) Age. (c) Sex. (c) Socioeconomic status. (e) Area of residence. *Clinical characteristics:* (f) Ophthalmic diagnosis groups within ophthalmic medical specialist care, multidisciplinary LVS patients could have been treated for more than one ophthalmic condition across the different diagnosis groups per year. (g) Comorbidities, multidisciplinary LVS patients could have been treated for both, mental and physical comorbidity. (h) Physical comorbidities on the diagnosis level, multidisciplinary LVS patients could have been treated within more than one of the medical specialism for comorbid physical disease per year. (i) Mental comorbidity on diagnosis level based on specialized mental healthcare, multidisciplinary LVS patients could have been treated for more than one comorbid



mental disorder per year. *Contextual characteristics*: (j) Distance to multidisciplinary LVS. (k) Type of institution, multidisciplinary LVS patients could have been treated in both, hospitals and independent treatment centers for ophthalmic medical specialist care. *Other healthcare utilization*: (l) Other healthcare utilization, utilization of multidisciplinary LVS patients of ophthalmic medical specialist care, GP care, low vision aids and occupational therapy and treatment with intravitreal injections. Intravitreal injections represent the number of multidisciplinary LVS patients that were treated with intravitreal injections for ophthalmic medical specialist care.

TABLE 1. Characteristics of the study population in 2015-2018 (N=49,726)

	2015 n=19,715	2016 n=18,046	2017 n=16,446	2018 n=16,829	Mean (4 years)
	n (%)	n (%)	n (%)	n (%)	%
Sociodemographic characteristics					
Sex, female, *n (%)*	10,705 (54.3)	9,865 (54.7)	9,003 (54.7)	9,046 (53.8)	54
Age, y, range 18-106, mean (SD)	64 (20)	64 (20)	64 (20)	64 (20)	
Socioeconomic status					
Missing	63 (0.3)	62 (0.3)	67 (0.4)	56 (0.3)	0
Low	7,508 (38.1)	6,843 (37.9)	6,241 (37.9)	6,338 (37.7)	38
Middle	7,602 (38.6)	6,916 (38.3)	6,131 (37.3)	6,319 (37.5)	38
High	4,542(23.0)	4,225(23.4)	4,007(24.4)	4,116 (24.5)	24
Area of residence					
Missing	20 (0.1)	21 (0.1)	13 (0.1)	12 (0.1)	0
Urban	13,392 (67.9)	12,123 (67.2)	11,204 (68.1)	11,476 (68.2)	68
Rural	6,303 (32.0)	5,902 (32.7)	5,229 (31.8)	5,341 (31.7)	32
Clinical characteristics					
Ophthalmic diagnosis group[†]					
Lens	1,466 (15.2)	1,475 (14.6)	1,261 (13.5)	1,346 (13.9)	14
Retina	1,018 (10.6)	1,126 (11.2)	1,078 (11.5)	1,127 (11.6)	11
Macular	3,587 (37.2)	3,742 (37.1)	3,380 (36.1)	3,392 (34.9)	36
Diabetic retina	528 (5.5)	528 (5.2)	492 (5.3)	440 (4.5)	5
Glaucoma	1,501 (15.6)	1,672 (16.6)	1,626 (17.4)	1,681 (17.3)	17
Neuro-ophthalmology	828 (8.6)	839 (8.3)	816 (8.7)	887 (9.1)	9
Others	2,551 (26.5)	2,694 (26.7)	2,438 (26.0)	2,606 (26.8)	26
Physical comorbidity	12,712 (64.5)	12,020 (66.6)	11,021 (67.0)	11,366 (67.5)	66
Mental comorbidity	2,376 (12.1)	2,338 (13.0)	2,223 (13.5)	2,336 (13.9)	13

TABLE 1. (continued)

	2015 n=19,715	2016 n=18,046	2017 n=16,446	2018 n=16,829	Mean (4 years)
	n (%)	n (%)	n (%)	n (%)	%
Contextual characteristics					
Type of institution‡					
Hospital	8,319 (86.3)	8,626 (85.5)	8,019 (85.6)	8,226 (84.7)	86
Independent treatment center	1,535 (15.9)	1,720 (17.1)	1,614 (17.2)	1,755 (18.1)	17
Distance to multidisciplinary LVS (km)					
Missing	20 (0.1)	21 (0.1)	13 (0.1)	12 (0.1)	0
0-9	8,720 (44.2)	7,922 (43.9)	7,205 (43.8)	7,535 (44.8)	44
10-19	6,385 (32.4)	5,833 (32.3)	5,403 (32.9)	5,491 (32.6)	33
20-29	3,455 (17.5)	3,190 (17.7)	2,780 (16.9)	2,739 (16.3)	17
30-39	866 (4.4)	826 (4.6)	770 (4.7)	779 (4.6)	5
40+	269 (1.4)	254 (1.4)	275 (1.7)	273 (1.6)	2
Other healthcare utilization					
Ophthalmic medical specialist care	9,637 (48.9)	10,084 (55.9)	9,371 (57.0)	9,710 (57.7)	55
Intravitreal injections§	1,788 (18.6)	1,749 (17.3)	1,587 (16.9)	1,643 (16.9)	17
GP care	15,274 (77.5)	14,120 (78.2)	13,222 (80.4)	13,772 (76.2)	78
Occupational therapy	1,188 (6.0)	1,218 (6.7)	1,186 (7.2)	1,353 (8.0)	7
LVAs	5,153 (26.1)	5,442 (30.2)	5,171 (31.4)	4,810 (28.6)	29

Abbreviations: GP care, general practitioner care; LVAs, low vision aids; SD, standard deviation
†Within ophthalmic medical specialist care, multidisciplinary LVS patients could have been treated for more than one ophthalmic condition per year.
‡Multidisciplinary LVS patients could have been treated in both, hospitals and independent treatment centers for ophthalmic medical specialist care.
§Multidisciplinary LVS patients that were treated with intravitreal injections within the ophthalmic medical specialist care.

TABLE 2. Results of GEE analysis: the effects of time (year) on patient characteristics

Outcome variables	2016[a]		2017[a]		2018[a]	
	OR [95%]	p	OR [95%]	p	OR [95%]	p
Sociodemographic characteristics						
Gender (Female)	1.00 [1.00-1.00]	>0.99	1.00 [1.00-1.00]	>0.99	1.00 [1.00-1.00]	>0.99
Age (≥65)	**1.05 [1.03-1.07]**	**0.002***	**1.12 [1.09-1.14]**	**0.002***	**1.21 [1.18-1.23]**	**0.002***
Socioeconomic status (low or middle)[b]	1.00 [0.98-1.02]	>0.99	1.00 [0.98-1.02]	>0.99	0.99 [0.97-1.00]	>0.99
Area of residence (Urban)	1.00 [0.98-1.02]	>0.99	1.00 [0.98-1.02]	>0.99	1.01 [0.99-1.03]	>0.99
Clinical characteristics						
Ophthalmic diagnosis group[c]						
Lens	0.95 [0.88-1.03]	>0.99	**0.87 [0.80-0.94]**	**0.006***	**0.88 [0.81-0.95]**	**0.02***
Retina	0.97 [0.86-1.09]	>0.99	0.95 [0.85-1.07]	>0.99	0.85 [0.70-1.43]	>0.99
Macular	0.98 [0.94-1.02]	>0.99	0.94 [0.90-0.98]	0.06	**0.90 [0.87-0.94]**	**0.02***
Diabetic Retina	1.03 [0.95-1.12]	>0.99	0.95 [0.86-1.05]	>0.99	**0.89 [0.80-0.98]**	**0.04***
Glaucoma	1.02 [0.89-1.17]	>0.99	1.00 [0.88-1.12]	>0.99	0.93 [0.75-1.16]	>0.99
Neuro-ophthalmology	0.98 [0.92-1.04]	>0.99	1.00 [0.92-1.07]	>0.99	0.99 [0.92-1.07]	>0.99
Others	1.00 [0.94-1.06]	>0.99	0.96 [0.91-1.02]	>0.99	0.98 [0.92-1.04]	>0.99
Physical comorbidity[c]	**1.21 [1.16-1.26]**	**0.002***	**1.21 [1.16-1.26]**	**0.002***	**1.25 [1.20-1.30]**	**0.002***
Mental comorbidity[c]	1.04 [0.98-1.04]	>0.99	1.07 [1.01-1.14]	0.59	1.09 [1.03-1.16]	0.11
Contextual characteristics						
Type of institution (Hospital)[d]	**0.92 [0.87-0.97]**	**0.02***	**0.91 [0.86-0.97]**	**0.04***	**0.86 [0.81-0.91]**	**0.002***
Distance to multidisciplinary LVS[†]	-0.04 [-0.43-0.35]	0.82	-0.01 [-0.07-0.05]	>0.99	-0.05 [-0.11-0.01]	>0.99
Other healthcare utilization[c]						
Ophthalmic medical specialist care	**1.23 [1.19-1.28]**	**0.002***	**1.25 [1.10-1.30]**	**0.02***	**1.23 [1.19-1.28]**	**0.002***
Intravitreal injections	0.92 [0.87-0.98]	0.15	**0.83 [0.77-0.88]**	**0.002***	**0.78 [0.72-0.84]**	**0.002***
GP care	0.97 [0.93-1.01]	>0.99	1.04 [1.00-1.08]	>0.99	**0.89 [0.85-0.92]**	**0.002***

TABLE 2. (continued)

Outcome variables	2016[a]		2017[a]		2018[a]	
	OR [95%]	p	OR [95%]	p	OR [95%]	p
Occupational therapy	**1.13 [1.04-1.22]**	**0.04***	**1.22 [1.13-1.32]**	**0.002***	**1.36 [1.26-1.48]**	**0.002***
LVAs	**1.20 [1.16-1.26]**	**0.002***	**1.26 [1.21-1.31]**	**0.002***	**1.09 [1.05-1.14]**	**0.002***

Abbreviations: GEE, general estimating equations; GP care, general practitioner care; LVAs, low vision aids; OR, odds ratio. Reference group: [a]2015; [b]high; [c]no utilization; [d]independent treatment center.
*Reported p-values are corrected. Bold is significant at $p<0.05$ (i.e. after Bonferroni correction).
†Regression coefficients obtained from the linear GEE analysis.

DISCUSSION

This study shows a decrease of Dutch multidisciplinary LVS patients by 15% between 2015 and 2018, and provides insight into possible explanations for this downward trend. The results demonstrated that multidisciplinary LVS patients were less likely to be treated with intravitreal injections over the years, with an overall decrease by 1.7%. As open data of the Dutch Healthcare Authority about the general population show an increase between 2015 and 2018 of intravitreal injections from 3.9% to 4.9%,[17] this could partly explain the downward trend in the study population, as people who received intravitreal injections utilized multidisciplinary LVS less over the years. Patients receiving medical treatment may feel a reduced need for multidisciplinary LVS, or might be referred less often by ophthalmologists as intravitreal injections substantially improve vision of patients and can enhance their quality of life.[35]

Multidisciplinary LVS patients were also less likely to have lens related diseases over the study period. This could be due to the rising number of cataract surgeries in Europe, including the Netherlands, as a result of demographic changes, good clinical outcomes, rapid postoperative recovery and a low risk of complications.[36] In Europe, cataract surgery is performed with good results in patients with an average preoperative decimal visual acuity of 0.27 (approximately 6/22), a mean age of 73 and in those who have ocular comorbidity such as macular degeneration or glaucoma[36], and can evidently improve their vision related quality of life.[37] It should be noted that changes for both intravitreal injections and lens related diseases were small, and can therefore only partially explain the downward trend in multidisciplinary LVS uptake.

In addition, findings revealed interesting trends in characteristics in the multidisciplinary LVS user population. Multidisciplinary LVS patients were more likely to have physical comorbidity over the years, possibly reflecting the increasing prevalence of multimorbidity in the general population due to demographic ageing, as reported by other studies [38,39] This implication is supported by the slight increase in multidisciplinary LVS patients who were 65 years or older across the years in the study population. On the other hand, higher rates of physical comorbidity in multidisciplinary LVS patients could also indicate greater access to and/or utilization of multidisciplinary LVS for people with more physical comorbidity. This is not in line with other studies that found major concurrent health problems to be a barrier for LVS utilization.[21] However, a possible explanation could be that the perceived need for multidisciplinary LVS by patients with comorbidity is higher as it may exacerbate the impact of vision loss.[38] In turn, being treated for other physical conditions might increase the chance of being referred. Another explanation could be the compulsory deductible that might be already be paid for other medical specialist care, which means that multidisciplinary LVS will be reimbursed by health insurance, hence lowering the barrier for multidisciplinary LVS access.[40]

Multidisciplinary LVS patients were more likely to be treated by an ophthalmologist over the years, which might reflect an increased knowledge of the referral guidelines and extensive implementation programs of the past 20 years. This finding is not consistent with other studies, in which the lack of referral to LVS by eye care professionals was found to be a major barrier to LVS access.[18,41] In turn, it might also indicate a barrier to access multidisciplinary LVS when a patient is not receiving treatment from an ophthalmologist or other medical specialist.

Interestingly, multidisciplinary LVS patients were more likely to utilize LVAs, which may indicate better access to specialized for-profit low vision optometrists and other nonprofit LVS, that also prescribe LVAs, or, increasing collaboration between these companies and multidisciplinary LVS. This differs from previous studies that suggested LVS patients experience a barrier for obtaining LVAs.[42] However, this referral pathway is in complete agreement with the Dutch referral guidelines.

Moreover, multidisciplinary LVS patients were mainly older adults over 65 years of age, female, had a low or middle SES, had macular related diseases and lived in urban areas within 20 km of multidisciplinary LVS locations.

Findings with respect to age, sex, ophthalmic condition and area of residence are also reported by other investigations,[19,41,43] and most can be explained by the epidemiological distribution of ophthalmic conditions and the Dutch population structure. As widely reported, the prevalence of visual impairment is increasing with age, with people above 50 years of age being particularly affected. Also, women are most likely to have visual impairment, and age-related macular degeneration has been reported as one of the leading causes of severe vision loss. Further, in the Netherlands around 70% of the population lives in cities, and approximately 30% lives in villages.[44] A discrepancy can be found with respect to SES. In contrast to multidisciplinary LVS patients in the study population of the present study who had mainly a low or middle SES, the general Dutch population predominately has a middle or high SES.[45] There is some evidence that SES is associated with visual impairment, as in people with low education, employment and/or income are at higher risk of developing visual impairment, even in developed countries.[46] This could be a plausible explanation for the SES distribution in the study population. On the other hand, visual impairment is associated with adverse outcomes for employment[9] and economic status.[47] Given this background, the present SES distribution in our study population might indicate a barrier to receive multidisciplinary LVS for visually impaired people with fewer resources, with regard to the SES indicators education, income and occupation. Although studies on barriers to LVS did not focus on SES, low income[18] and low education[41] were found to be prohibitive factors for utilizing or having access to LVS in studies in countries where LVS are not or only partially paid for by the public health system. More research on the role of SES in the access to and/or utilization of multidisciplinary LVS is needed.

A point of interest is the regional distribution of multidisciplinary LVS patients. It is expected that in the Netherlands by 2035, the number of people aged 65 or older will increase, particularly in rural areas due to demographic aging and young people moving to urban areas.[48] Policy makers should be aware of this population shift and possible emerging disparities in the access to multidisciplinary LVS based on area of residence as most multidisciplinary LVS patients currently live in urban areas. The fact that most multidisciplinary LVS patients in the study population lived within 20 km of multidisciplinary LVS can be explained by the high population density and the good geographical coverage of multidisciplinary LVS in the Netherlands.

This study has some limitations. First, this study reflects the Dutch situation and the way multidisciplinary LVS are offered, whereas the method whereby patients are referred to LVS varies across countries. LVS may be offered by multidisciplinary practitioners or in a single service, as part of an ophthalmology departments in hospitals, and, may be reimbursed by health insurance or not. Furthermore, there is a difference in how LVS are defined and whether or not LVAs and optometry are included in the definition. Because of this country specific LVS care delivery system and definitions, one-to-one comparisons should be made with caution. Nevertheless, the results of the present study regarding the downward trend in multidisciplinary LVS patients and characteristics can be considered as informative for other countries.

Second, in contrast to other countries, the DTC diagnosis codes are not in accordance with the International Classification of Diseases, 10th revision (ICD-10). Although DTC diagnoses are based on the ICD-10 structure for their classification, ICD-10 diagnoses themselves are not used within DTC, which has different diagnoses options. Therefore, the present findings regarding ophthalmic diagnoses and physical comorbidity in multidisciplinary LVS patients cannot be compared directly with results from international studies.

Third, study results could be concerned with coding errors or misdiagnosis, which can be a flaw in any study based on healthcare insurance claims.[49] However, a recent validation study in a cardiac population indicated that Dutch healthcare claims data are highly accurate.[50]

Fourth, in view of international studies where the severity of visual impairment was found to be strongly related to the likelihood of patients receiving LVS,[20,22] the role of visual acuity and the severity of the visual impairment in the downward trend in multidisciplinary LVS patients could not be assessed, as these data were not available.

Fifth, this study only included care that was covered by health insurance, and therefore these results might not represent accurately the actual healthcare utilization and characteristics of the study population.

Sixth, as this study only includes healthcare claims data of multidisciplinary LVS within the HIA, which was introduced in 2015, the impact of the shift to this new healthcare policy could not be observed here.

A major strength of this study was the use of a large population-based dataset, which includes the claims data of all Dutch insurers covering almost all multidisciplinary LVS delivered within the HIA, and thus enhances generalizability to the Dutch multidisciplinary LVS population.

Conclusion

Between 2015 and 2018, the number of Dutch multidisciplinary LVS patients decreased by 15%. This decrease in uptake might, at least partially, be explained by a decreased distribution of patients treated with intravitreal injections and patients with lens related diseases within multidisciplinary LVS. In 2016, 2017 and 2018, multidisciplinary LVS patients were more likely to have physical comorbidity and to utilize ophthalmic care, LVAs and occupational therapy compared to 2015. This might indicate enhanced access to multidisciplinary LVS when treated by ophthalmologists or within other medical specialties, or the opposite, i.e., less access to multidisciplinary LVS when not treated within one of these medical specialties. In addition, multidisciplinary LVS patients with multimorbidity might have experienced fewer barriers to multidisciplinary LVS because of the compulsory deductible that had already been made. Policymakers should pay attention to possible emerging regional disparities in access to and/or utilization of multidisciplinary LVS. Given these current results, future studies should further investigate further these differences in characteristics between multidisciplinary LVS users and non-users.

REFERENCES

1. Bourne R, Steinmetz JD, Flaxman S, Briant PS, Taylor HR, Resnikoff S, et al. Trends in prevalence of blindness and distance and near vision impairment over 30 years: an analysis for the Global Burden of Disease Study. *Lancet Glob Health.* 2021;9(2):e130-e43.
2. Liu YC, Wilkins M, Kim T, Malyugin B, Mehta JS. Cataracts. *Lancet.* 2017;390(10094):600-12.
3. Flaxman SR, Bourne RRA, Resnikoff S, Ackland P, Braithwaite T, Cicinelli MV, et al. Global causes of blindness and distance vision impairment 1990-2020: a systematic review and meta-analysis. *Lancet Glob Health.* 2017;5(12):e1221-e34.
4. Lamoureux EL, Fenwick E, Moore K, Klaic M, Borschmann K, Hill K. Impact of the severity of distance and near-vision impairment on depression and vision-specific quality of life in older people living in residential care. *Invest Ophthal Vis Sci.* 2009;50(9):4103-9.
5. Kempen GI, Ballemans J, Ranchor AV, van Rens GH, Zijlstra GA. 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. *Qual Life Res.* 2012;21(8):1405-11.
6. van der Aa HPA, Comijs HC, Penninx BWJH, van Rens GHMB, van Nispen RMA. Major Depressive and Anxiety Disorders in Visually Impaired Older Adults. *Invest Ophthal Vis Sci.* 2015;56(2):849-54.
7. van Nispen RM, Vreeken HL, Comijs HC, Deeg DJ, van Rens GH. Role of vision loss, functional limitations and the supporting network in depression in a general population. *Acta Ophthalmol.* 2016;94(1):76-82.
8. de Boer MR, Pluijm SM, Lips P, Moll AC, Volker-Dieben HJ, Deeg DJ, et al. Different aspects of visual impairment as risk factors for falls and fractures in older men and women. *J Bone Miner Res.* 2004;19(9):1539-47.
9. Köberlein J, Beifus K, Schaffert C, Finger RP. The economic burden of visual impairment and blindness: a systematic review. *BMJ open.* 2013;3(11):e003471.
10. Owsley C, McGwin G, Jr, Lee PP, Wasserman N, Searcey K. Characteristics of Low-Vision Rehabilitation Services in the United States. *Arch Ophthalmol.* 2009;127(5):681-9.
11. Lim YE, Vukicevic M, Koklanis K, Boyle J. Low Vision Services in the Asia-Pacific Region: Models of Low Vision Service Delivery and Barriers to Access. *J Vis Impair Blind.* 2014;108(4):311-22.
12. van Nispen RMA, Virgili G, Hoeben M, Langelaan M, Klevering J, Keunen JEE, et al. Low vision rehabilitation for better quality of life in visually impaired adults. *Cochrane Database Syst Rev.* 2020(1).
13. van der Aa HPA, van Rens GHMB, Bosmans JE, Comijs HC, van Nispen RMA. Economic evaluation of stepped-care versus usual care for depression and anxiety in older adults with vision impairment: randomized controlled trial. *BMC Psychiatry.* 2017;17(1):280.
14. Pollard TL, Simpson JA, Lamoureux EL, Keeffe JE. Barriers to accessing low vision services. *Ophthalmic Physiol Opt.* 2003;23(4):321-7.
15. Significant. Zorg en begeleiding voor zintuiglijke gehandicapten [Care and guidance for the sensory disabled] 2016 [cited 2021 Dec 11]. Available from: https://www.tweedekamer.nl/kamerstukken/detail?id=2016D50851&did=2016D50851.
16. Royal Dutch Visio. Visio Jaardocument 2015 [Visio annual report 2015] [cited 2020 Sep 1]. Available from: https://adoc.pub/jaarverslag-koninklijke-visio-expertisecentrum-voor-slechtzi0dc332180e2c7930faceee57c715e3a346994.html.
17. Dutch Healthcare Authority. Open data van de Nederlandse Zorgautoriteit [Open data of the Dutch Healthcare Authority] 2014-2021 [cited 2021 Jul 2]. Available from: www.opendisdata.nl/.
18. Lam N, Leat SJ. Reprint of: Barriers to accessing low-vision care: the patient's perspective. *Can J Ophthalmol.* 2015;50 Suppl 1:S34-9.

19. Basilious A, Basilious A, Mao A, Hutnik CML. Trends in low vision care provided by ophthalmologists in Ontario between 2009 and 2015. *Can J Ophthalmol.* 2019;54(2):229-36.
20. Goldstein JE, Guo X, Boland MV, Swenor BK. Low Vision Care - Out of Site. Out of Mind. *Ophthalmic Epidemiol.* 2020:1-7.
21. Matti AI, Pesudovs K, Daly A, Brown M, Chen CS. Access to low-vision rehabilitation services: barriers and enablers. *Clin Exp Optom.* 2011;94(2):181-6.
22. Kaleem MA, West SK, Im L, Swenor BK. Referral to Low Vision Services for Glaucoma Patients: Referral Criteria and Barriers. *J Glaucoma.* 2018;27(7):653-5.
23. Lam N, Leat SJ, Leung A. Low-vision service provision by optometrists: a Canadian nationwide survey. *Optom Vis Sci.* 2015;92(3):365-74.
24. van der Aa HP, Hoeben M, Rainey L, van Rens GH, Vreeken HL, van Nispen RM. Why visually impaired older adults often do not receive mental health services: the patient's perspective. *Qual Life Res.* 2015;24(4):969-78.
25. Cuypers M, Tobi H, Huijsmans CAA, van Gerwen L, Ten Hove M, van Weel C, et al. Disparities in cancer-related healthcare among people with intellectual disabilities: A population-based cohort study with health insurance claims data. *Cancer medicine.* 2020;9(18):6888-95.
26. Farej R, Batt K, Afonja O, Martin C, Aubert R, Carlyle M, et al. Characterizing female patients with haemophilia A: Administrative claims analysis and medical chart review. *Haemophilia..* 2020;26(3):520-8.
27. World Health Organization. Universal eye health: a global action plan 2014-2019. 2013 2020 Oct 3. Report No.: 9789241506564.
28. Kroneman M, Boerma W, van den Berg M, Groenewegen P, de Jong J, van Ginneken E. Netherlands: Health System Review. *Health syst transit.* 2016;18(2):1-240.
29. Vektis. Verzekerden in beeld [Insured in the picture] 2021 [cited 2021 Mar 3]. Available from: www.vektis.nl/uploads/Publicaties/Zorgthermometer/Zorgthermometer%20Verzekerden%20in%20Beeld%202021.pdf.
30. van Rens GHMB, Vreeken HL, van Nispen RMA. Richtlijn visusstoornissen revalidatie en verwijzing [Guideline vision disorders: rehabilitation and referral] 2011 [cited 2020 Sep 20]. Available from: http://www.vivis.nl/wp-content/uploads/2019/10/Richtlijn-visusstoornissen-revalidatie-en-verwijzing.pdf.
31. The Netherlands Institute for Social Research. Statusscores 2017. 2017.
32. Statistics Netherlands. Buurt, wijk en gemeente 2020 voor postcode huisnummer [Neighborhood, district and municipality 2020 for postcode house number] 2020 [updated 2020 Oct 6; cited 2020 Oct 22]. Available from: www.cbs.nl/nl-nl/maatwerk/2020/39/buurt-wijk-en-gemeente-2020-voor-postcode-huisnummer.
33. Statistics Netherlands. Degree of Urbanisation 2021 [cited 2021 Jan 3]. Available from: www.cbs.nl/en-gb/onze-diensten/methods/definitions/degree-of-urbanisation.
34. Little RJ, Rubin DB. Statistical analysis with missing data: John Wiley & Sons; 2019.
35. Finger RP, Wiedemann P, Blumhagen F, Pohl K, Holz FG. Treatment patterns, visual acuity and quality-of-life outcomes of the WAVE study – A noninterventional study of ranibizumab treatment for neovascular age-related macular degeneration in Germany. *Acta Ophthalmol.* 2013;91(6):540-6.
36. Lundström M, Dickman M, Henry Y, Manning S, Rosen P, Tassignon M-J, et al. Changing practice patterns in European cataract surgery as reflected in the European Registry of Quality Outcomes for Cataract and Refractive Surgery 2008 to 2017. *J Cataract Refract Surg.* 2021;47(3):373-8.

37. Lamoureux EL, Fenwick E, Pesudovs K, Tan D. The impact of cataract surgery on quality of life. *Curr Opin Ophthalmol.* 2011;22(1):19-27.
38. Marengoni A, Angleman S, Melis R, Mangialasche F, Karp A, Garmen A, et al. Aging with multimorbidity: A systematic review of the literature. *Ageing Res Rev.* 2011;10(4):430-9.
39. Statistics Netherlands. Population pyramid 2021 [cited 2021 Jul 3]. Available from: www.cbs.nl/en-gb/visualisations/dashboard-population/population-pyramid.
40. Itz CJ, Ramaekers BL, van Kleef M, Dirksen CD. Medical specialists care and hospital costs for low back pain in the Netherlands. *Eur J Pain (London, England).* 2017;21(4):705-15.
41. Overbury O, Wittich W. Barriers to low vision rehabilitation: the Montreal Barriers Study. *Invest Ophthalmol Vis Sci.* 2011;52(12):8933-8.
42. Sivakumar P, Vedachalam R, Kannusamy V, Odayappan A, Venkatesh R, Dhoble P, et al. Barriers in utilisation of low vision assistive products. *Eye.* 2020;34(2):344-51.
43. Chong MF, Jackson AJ, Wolffsohn JS, Bentley SA. An update on the characteristics of patients attending the Kooyong Low Vision Clinic. *Clin Exp Optom.* 2016;99(6):555-8.
44. The Netherlands Institute for Social Research. Dorpsleven tussen stad en land [Village life between city and countryside] 2017 [cited 2021 Jun 4]. Available from: www.scp.nl/publicaties/publicaties/2017/03/30/dorpsleven-tussen-stad-en-land.
45. Volksgezondheidenzorg.info. Sociaaleconomische status [Socioeconomic status] 2021 [cited 2021 Aug 1]. Available from: www.volksgezondheidenzorg.info/onderwerp/sociaaleconomische-status/regionaal-internationaal/regionaal#!node-sociaaleconomische-status.
46. Whillans J, Nazroo J. Social Inequality and Visual Impairment in Older People. *J Gerontol B Psychol Sci Soc Sci.* 2016;73(3):532-42.
47. Cumberland PM, Rahi JS, Eye ftUB, Consortium V. Visual Function, Social Position, and Health and Life Chances: The UK Biobank Study. *JAMA ophthalmology.* 2016;134(9):959-66.
48. Statistics Netherlands. Sterke groei in steden en randgemeenten verwacht [Strong growth in cities and suburbs expected] 2019 [cited 2021 Aug 25]. Available from: www.cbs.nl/nl-nl/nieuws/2019/37/sterke-groei-in-steden-en-randgemeenten-verwacht.
49. Stein JD, Lum F, Lee PP, Rich WL, 3rd, Coleman AL. Use of health care claims data to study patients with ophthalmologic conditions. *Ophthalmology.* 2014;121(5):1134-41.
50. Eindhoven DC, van Staveren LN, van Erkelens JA, Ikkersheim DE, Cannegieter SC, Umans VAWM, et al. Nationwide claims data validated for quality assessments in acute myocardial infarction in the Netherlands. *Neth Heart J.* 2018;26(1):13-20.

CHAPTER 4

Big data study using health insurance claims to predict multidisciplinary low vision service uptake

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Optometry and Vision Science. 2024; 101(6):290-297.
doi: 10.1097/OPX.0000000000002134

ABSTRACT

Significance

There is a lack of research from high-income countries with various healthcare and funding systems regarding barriers and facilitators in low vision services (LVS) access. Furthermore, very few studies on LVS provision have used claims data.

Purpose

This study aimed to investigate which patient characteristics predict receiving multidisciplinary LVS in the Netherlands, a high-income country, based on healthcare claims data.

Methods

Data from a Dutch national health insurance claims database (2015 to2018) of patients with eye diseases causing potentially severe visual impairment were retrieved. Patients received multidisciplinary LVS (n=8,766) and/or ophthalmic treatment in 2018 (reference, n=565,496). Multidisciplinary LVS is provided by professionals from various clinical backgrounds, including non-profit low vision optometry. Patient characteristics (sociodemographic, clinical, contextual, general healthcare utilization) were assessed as potential predictors using a multivariable logistic regression model, which was internally validated with bootstrapping.

Results

Predictors for receiving multidisciplinary LVS included prescription of low vision aids (odds ratio [OR], 8.76; 95% confidence interval [CI], 7.99 to 9.61), having multiple ophthalmic diagnoses (OR, 3.49; 95%CI, 3.30 to 3.70), receiving occupational therapy (OR, 2.32; 95%CI, 2.15 to 2.51), mental comorbidity (OR, 1.17; 95%CI, 1.10 to 1.23), comorbid hearing disorder (OR, 1.98; 95%CI, 1.86 to 2.11), receiving treatment in both a general hospital and a specialized ophthalmic center (OR, 1.23; 95%CI, 1.10 to 1.37), or by a general practitioner (OR, 1.23; 95%CI, 1.18 to 1.29). Characteristics associated with lower odds included older age (OR, 0.30; 95%CI, 0.28 to 0.32), having a low social economic status (OR, 0.91; 95%CI, 0.86 to 0.97), physical comorbidity (OR, 0.87; 95%CI, 0.82 to 0.92) and greater distance to an MLVS (OR, 0.95; 95%CI, 0.92 to 0.98). The area under the curve (AUC) of the model was: AUC=0.75 (95%CI, 0.75 to 0.76; optimism=0.0008).

Conclusions

Various sociodemographic, clinical and contextual patient characteristics, as well as factors related to patients' general healthcare utilization, were found to influence multidisciplinary LVS receipt as barriers or facilitators. Eye care practitioners should have attention for socioeconomically disadvantaged older patients when considering multidisciplinary LVS referral.

INTRODUCTION

It is well known that visual impairment can have a large toll on an individual's quality of life.[1] Low vision services (LVS) aim to enhance quality of life,[2] but internationally, there is a great variation in how these services are offered. It may consist of mental healthcare to help individuals adjust to their impairment, practical advice and living skills training (e.g., cooking, braille), mobility and orientation training, and prescription of low vision aids (LVAs) and training in their practical use.[2,3] LVS may be provided in a single service model where, for example, one organization provides mental healthcare and another prescribes LVAs. There are also multidisciplinary LVS, where one organization provides the full range of services with professionals from various clinical backgrounds, such as psychologists, social workers, occupational therapists, mobility trainers, and low vision optometrists, who work together in a multidisciplinary team. Furthermore, LVS may be offered by nonprofit, for-profit, and/or charity organizations.

Although research demonstrating effectiveness of low vision services is limited, few studies have found a positive effect of some LVS on visual functioning, mental health, and quality of life.[4] Furthermore, the importance of LVS has been recognized by the World Health Organization, which has stimulated the enhancement and access to LVS in its global action plan to allow individuals to profit from these services.[5]

However, studies have found various factors that may prevent low vision service access. Lack of intrinsic motivation, misconceptions about LVS, geographical location, costs, stigma, or lack of information provision, among others, may serve as barriers.[6-9] In turn, facilitators include increased severity of vision loss, good patient-doctor communication, higher education level, and more social support.[6,7,9,10]

In these studies, barriers and facilitators were mainly investigated in low-income countries, with qualitative research techniques or using cross-sectional designs. There is a lack of research from high-income countries where healthcare and funding systems are organized differently. Furthermore, in the past decade, research based on healthcare claims data, routinely collected for billing purposes of medical services to health insurers, has gained interest.[11,12] These data are collected on a large scale and may include patient demographics, clinical data, and medical procedures. They are therefore of high potential for research purposes, providing rich data to examine patterns in healthcare utilization, disparities between populations, and informing health policy. The objective of this study is to investigate which patient characteristics predict receiving LVS in a high-income country, that is, the Netherlands, based on healthcare claims data, with a focus on nonprofit multidisciplinary LVS. Very few studies have used claims data to investigate barriers and facilitators in the access to LVS, which makes this study a valuable contribution to the literature in this area.[8,13]

METHODS

This research was reviewed by an independent ethical review board and conforms with the principles and applicable guidelines for the protection of human subjects in biomedical research. The study protocol was approved by the Medical Ethics Committee of Amsterdam University Medical Centers, location VUmc.

We present a retrospective big data study based on healthcare insurance claims designed to gain insight into predictors for receiving multidisciplinary LVS.

The Dutch health insurance system

According to the Dutch Health Insurance Act (HIA), everyone who lives and/or works in the Netherlands is legally obliged to take out a basic statutory health insurance.[14,15] Based on solidarity, everyone receives a basic insurance and contributes to the financing of healthcare by paying annual premiums, a compulsory deductible, and taxes.

In summary, the basic statutory insurance includes general practitioner care, maternity care, inpatient and outpatient medical specialist care (hospital care), home nursing care, pharmaceutical care, and mental healthcare, but also multidisciplinary LVS and LVAs. The average basic annual premium was 1,158 euros in 2015 and 1,308 euros in 2018[16]; the income-dependent annual premium was 6.95% of income for employees and 4.85% for self-employed persons in 2015, and 6.90% of income for employees and 5.65% for self-employed in 2018.[14,17] There are some exceptions (e.g., for general practitioner care), but every citizen needs to pay the first 385 euros out of pocket. People with low income can receive a healthcare benefit for the basic statutory insurance. For healthcare that is not covered by basic insurance, individuals can purchase an extra (voluntary) health insurance package, which covers additional care (e.g., dental care, mental healthcare or LVAs).

Low vision services

In the Netherlands, LVS are offered by three nonprofit multidisciplinary rehabilitation organizations (Royal Dutch Visio, Bartiméus, and the Robert Coppes Foundation) and by for-profit specialized low vision optometrists.

LVS provided at the multidisciplinary organizations comprise a range of services aimed at enhancing independence and functioning in daily life, for example, advice, prescription and training in the use of LVAs, advice for optimal lighting, training in orientation and mobility and daily living skills (e.g., cooking, reading, self-care), computer training, and mental healthcare. These services are provided by, among others, social workers, psychologists, optometrists, low vision optometrists, and occupational therapists. They are, as of 2015, largely funded by health insurance within the basic statutory health insurance.

Low vision optometry provided by for-profit low vision optometrists comprises visual functioning examinations and prescribing and fitting optical LVAs, such as magnifiers and

telescope glasses. For-profit low vision optometrists mostly work at specialized low vision companies. Besides hospitals and specialized optical shops, some companies also offer their services to patients at home. In this study, we defined LVS as care provided at the multidisciplinary organizations, including the broad range of nonprofit services, and not to for-profit low vision optometry, as it was not adequately represented in the claims data; that is, it could not be distinguished from the broader type of optometry in the Netherlands, which does not include LVAs. In the Netherlands, an estimated 22,000 patients receive for-profit low vision optometry annually, including checkup appointments, new patients, and healthcare that is not reimbursed by health insurance (personal communication). Of the 22,000, approximately 12,000 (55%) are referred to multidisciplinary LVS annually, of which around 20% (~2400) actually utilize these services.

Referral

The Dutch Society of Ophthalmology advises referral to multidisciplinary low vision service organizations in their guideline (2011 to 2020) for people with a decimal visual acuity of <0.3 and/or a visual field of <30° around the central point of fixation and/or an evident request for assistance when therapeutic options in regular ophthalmic practice are not sufficient.[18]

All medical specialists are allowed to refer patients, but in practice, ophthalmologists form the largest group of referring specialists. Besides that, low vision optometrists are allowed to refer patients in accordance with the ophthalmologist. According to the referral guideline, patients should be referred to the for-profit low vision optometrist, when visual functioning can be (partially) improved or compensated with optical aids. Patients should be referred to multidisciplinary LVS if low vision optometry does not fully meet a patient's needs.

Study population

For this study, claims data between January 1, 2015 and December 31, 2018 of patients with eye diseases related to severe vision loss were retrieved from Vektis C.V., an organization that routinely collects and monitors healthcare claims data of all Dutch health insurers.

Patients in the target group were included in the dataset if they were 18 years or older with any ophthalmic diagnosis and received LVS provided at the multidisciplinary low vision service organizations in 2018. The selection of the reference group was based on ophthalmic treatment in 2018. This group contained patients treated for glaucoma, diabetic retinal, retinal, and/or macular diseases who did not receive multidisciplinary LVS. For both groups, patients who received multidisciplinary LVS in 2015 to 2017 were excluded. We selected the reference group in such a way that we would most likely select patients with a visual impairment and thus patients who were eligible for referral to multidisciplinary LVS (Appendix Table A1). For setting the selection criteria, we first examined the target

group (patients who received multidisciplinary LVS in 2018) and identified the most prevalent eye diseases leading to visual impairment in their claims data, which were the aforementioned eye disease groups that commonly lead to irreversible visual impairment in high-income countries.

Patient characteristics

Sociodemographic characteristics

Sex, age, socioeconomic status (SES), area of residence, and region of residence were retrieved from the claims data. SES was based on information from The Netherlands Institute for Social Research, which calculates low, middle, or high SES based on income, education, and occupation.

Area and region of residence were investigated by linking four-digit postal codes within the claims data to an open dataset from Statistics Netherlands with information about Dutch regions (north, east, south, and west) and degree of urbanization of Dutch municipalities. Five degrees of urbanization were distinguished, which are based on the surrounding address density per square kilometer: extremely urbanized (2500 surrounding addresses or more), strongly urbanized (1500 to 2500 surrounding addresses), moderately urbanized (1000 to 1500), hardly urbanized (500 to 1000), and not urbanized (less than 500). For this study, we first investigated urbanization level per patient and then recoded them into urban and rural area of residence, whereby the first was based on the three highest degrees of urbanization and the latter on the two lowest degrees of urbanization. Furthermore, we investigated if patients were living in the north, east, south, or west of the Netherlands. Data from 2017 were used to determine SES and postal codes, and data from 2018 were used to determine sex and age.

Clinical characteristics

Treatment in ophthalmic care, ophthalmic diagnosis, costs for ophthalmic encounters, cataract surgery, intravitreal injections, optical coherence tomography scans, visual field tests, physical comorbidity, and mental comorbidity were selected from the claims data. First, we calculated the number of unique ophthalmic diagnoses per patient as assessed between 2015 and 2018. We specifically looked at glaucoma and diabetic retinal, retinal, and macular diseases. Other diagnoses were categorized into ophthalmic diagnosis "other" and were not included in the number of ophthalmic diagnoses. In addition, cataract surgery and intravitreal injections were investigated, as were the total number of cataract surgeries, injections, optical coherence tomography scans, and visual field tests per patient within 2015 to 2017. Physical comorbidity was defined as having at least one cost registration within the years 2015 until 2017 within at least one medical specialty other than ophthalmology. Besides that, we also investigated if patients had hearing disorders (deafness, hearing impairment, and vestibular disorders), which was defined

as having at least one cost registration for hearing disorders in the 3-year period. Mental comorbidity was based on claims data from mental healthcare, comprising of basic and specialized mental healthcare, care provided by mental health practice nurses in general practitioner care, and psychological care provided within the medical specialist care. We defined mental comorbidity as having at least one cost registration within 2015 until 2017 for any of these types of mental healthcare.

Contextual characteristics

With respect to contextual characteristics, we examined the distance to multidisciplinary LVS and ophthalmic treatment setting where patients received ophthalmic care. Distance to multidisciplinary LVS was determined with the Google Maps ruler function based on four-digit postal codes and locations of multidisciplinary low vision service centers. For each Dutch four-digit postal code (~4000), we first estimated the distance to a multidisciplinary low vision service center in kilometers (km) with the Google ruler, assuming that patients would go to the nearest location. We then joined these data to patients' 2017 four-digit postal codes.

For ophthalmic treatment setting, we investigated on the basis of ophthalmology treatments whether patients had been treated at a general hospital, a specialized ophthalmic center (e.g., specialized in macular degeneration or glaucoma), or both types of care institutions. Patients whose type of institution treated was missing were categorized as "missing," and those who were not treated in ophthalmic medical specialized care were classified as such.

Other healthcare utilization

Patients' utilization of general practitioner care, occupational therapy, and LVAs was examined as well.

A general practitioner encounter and occupational therapy were defined as having at least one costs registration within 2015 until 2017. Furthermore, for general practitioner encounters, we calculated the total costs per patient between 2015 and 2017. In the Netherlands, occupational therapy can be a part of multidisciplinary LVS or may also be offered outside the context of multidisciplinary LVS. Our study focused on occupational therapy provided outside the context of multidisciplinary LVS.

Regarding LVAs, we first needed to select these specific LVAs, as we had access to reimbursements made for all types of visual aids, including contact lenses and spectacles for refractive errors, which were excluded. We also calculated the number of prescribed LVAs per person, by summarizing the number of reimbursements. Finally, we also calculated total LVAs costs per patient between 2015 and 2017.

Data analysis

All analyses were conducted with SAS software version 9.4 (SAS Institute Inc., Cary, NC) and EXCEL (Microsoft Corporation, Redmond, WA; 2016). Descriptive statistics were used to investigate patient characteristics. To predict receiving multidisciplinary LVS as the dependent variable, we used multivariable logistic regression models with sociodemographic, clinical and contextual characteristics and other healthcare utilization as potential predictors. The selection of predictors was based on the literature, clinical expertise from the authors, and insights gained from our previous studies.[6-8,10,13]

There were missing data for SES, area of residence, region of residence, amount of ophthalmic diagnoses, and distance to multidisciplinary LVS, with a proportion of missing data varying between 1% and 26% for each of the two subgroups. The missing data were assumed to be missing at random.[19] The imputation method proposed by Lanning and Berry was used,[20] after multiple imputation proved to be prohibitively computationally extensive for our large data set. With this method, a random replacement value for every missing value in the dataset is created based on the nonmissing minimum and range of the respective variable with missing values.

On the basis of the imputed dataset, we ran the multivariable logistic regression model with all potential variables and first tested assumptions: linearity between continuous predictors and the outcome, outliers, and collinearity. We examined bivariate collinearity by examining the correlation matrix (Spearman correlation) of all candidate predictors. We excluded variables when they had a correlation of >0.5 or <-0.5 with another variable. The following variables were excluded because of collinearity: type of mental healthcare, psychological diagnosis (anxiety and depression), and number of cataract surgeries, intravitreal injections, and visual field tests. Furthermore, for the remaining variables, the variance inflation factor was calculated to examine multicollinearity. A variance inflation factor of >5 was considered to be indicative for multicollinearity, but no multicollinearity was observed. Age, costs for ophthalmic encounters, number of optical coherence tomography scans, and distance to multidisciplinary LVS were log-transformed as the assumption of linearity with the log-odds of the outcome was violated. Outliers were examined with logistic regression diagnostics, among which were Pearson residuals and deviance residuals.[21]

Multivariable logistic regression was performed with the remaining variables, whereby a p-value of 0.05 was considered statistically significant after Benjamini and Hochberg correction for multiple testing.[22] The area under the receiver operating characteristic curve was calculated to examine the predictive accuracy of the model.[23] Bootstrapping was used for internal validation of the model and for calculating optimism-corrected area under the receiver operating characteristic curve.[24]

RESULTS

Between January 1, 2018, and December 31, 2018, 8766 patients received multidisciplinary LVS, whereas 565,496 patients did not receive multidisciplinary LVS but were treated for glaucoma, diabetic retinal, retinal, and/or macular diseases within the ophthalmic medical specialist care (Table 1, Appendix Table A2). Of the patients who utilized multidisciplinary LVS in 2018, 39.4% were not treated within the ophthalmic medical specialist care in 2015 to 2017.

As presented in Table 1 and Appendix Table A2, of the entire study population (574,262), the majority was female, aged 65+ (range, 18 to 106 years), with a (middle) high SES, and living in urban areas. Over three-quarters lived within 20 km from a multidisciplinary LVS center. Furthermore, almost half of the study population had glaucoma and a quarter macular-related diseases. The mean age of multidisciplinary LVS users was higher for all ophthalmic conditions compared with multidisciplinary LVS nonusers, except for retinal diseases (mean=65.23, SD=18.98 in multidisciplinary LVS users vs. mean=67.25, SD=13.88 in multidisciplinary LVS nonusers). Besides that, over 80% had physical comorbidity and 14% had mental comorbidity.

The majority was treated in a general hospital for ophthalmic medical specialist care, 14% had cataract surgery, and 9% was treated with intravitreal injections. Regarding other healthcare utilization, over a third had a general practitioner encounter, 4% had occupational therapy, and 1% received a prescription for LVAs. Overall, multidisciplinary LVS users had higher average costs for all types of healthcare compared with multidisciplinary LVS nonusers, except for ophthalmic encounters.

Testing assumptions

Outlier identification revealed 6,405 observations (1.1% of total study population) to be influential and thus 566,857 (98.9% of the study population) to be not. Further analysis showed that most of the multidisciplinary LVS users were represented in the group of outliers (73.1% multidisciplinary LVS users in the group outliers vs. 0.42% multidisciplinary LVS users in the group of nonoutliers). This suggests that the outliers should be included in the analysis and that one or more covariates are strongly predictive of multidisciplinary LVS use in 2018, which we further examined with multivariable logistic regression and in a sensitivity analysis.

TABLE 1. Main characteristics of the study population (N=574,262)

	MLVS users (n=8,766) n (%)	MLVS nonusers (n=565,496) n (%)	Total (N=574,262) n (%)
Sex, female	4,636 (52.9)	303,354 (53.6)	307,990 (53.6)
Age (y), range 18-106, mean (SD)	65.27 (19.61)	69.68 (13.38)	69.61 (13.51)
Ophthalmic diagnosis group*			
Retina			
Missing	2,294 (26.2)	0 (0)	2,294 (0.4)
Yes	846 (9.7)	76,830 (13.6)	77,676 (13.5)
No	5,626 (64.2)	488,666 (86.4)	494,292 (86.1)
Macular			
Missing	2,294 (26.2)	0 (0)	2,294 (0.4)
Yes	2,462 (28.1)	148,567 (26.3)	151,029 (26.3)
No	4,010 (45.7)	416,929 (73.7)	420,939 (73.3)
Diabetic retina			
Missing	2,294 (26.2)	0 (0)	2,294 (0.4)
Yes	446 (5.1)	139,729 (24.7)	140,175 (24.4)
No	6,026 (68.7)	425,767 (75.3)	431,793 (75.2)
Glaucoma			
Missing	2,294 (26.2)	0 (0)	2,294 (0.4)
Yes	1,171 (13.4)	263,234 (46.5)	264,405 (46.0)
No	5,301 (60.5)	302,262 (53.5)	307,563 (53.6)
Others			
Missing	2,294 (26.2)	0 (0.0)	2,294 (0.4)
Yes	4,425 (50.5)	274,203 (48.5)	278,628 (48.5)
No	2,047 (23.4)	291,293 (51.5)	293,340 (51.1)

Data are n/n (%) or n/N (%), unless otherwise specified. Abbreviations: MLVS, multidisciplinary low vision services; SD, standard deviation.
*Within ophthalmic medical specialist care based on the years 2015-2018. MLVS patients could have been treated for more than one ophthalmic condition in 2015-2018. There are 2294 missing values for all ophthalmic conditions for MLVS users, because the missing values are related to patients who have not been treated within ophthalmic medical specialists care.

TABLE 2. Results of multivariable logistic regression analysis: patient characteristics as predictors for receiving multidisciplinary low vision services (N=574,262)

Independent variables	Model based on imputed data	
	OR [95% CI]	p*
Sociodemographic characteristics		
Sex (female)	1.00 [0.96-1.04]	0.999
Age	**0.30 [0.28-0.32]**	**<0.0001**
Socioeconomic status[a]		
Low	**0.91 [0.86-0.97]**	**0.002**
Middle	0.95 [0.89-1.00]	0.06
Area of residence (urban)	0.95 [0.90-1.00]	0.05
Region of residence[b]		
North	**1.59 [1.48-1.72]**	**<0.0001**
East	**1.23 [1.56-1.30]**	**<0.0001**
South	**1.37 [1.29-1.45]**	**<0.0001**
Clinical characteristics		
Amount of ophthalmic diagnoses (2 or more)	**3.49 [3.30-3.70]**	**<0.0001**
IVIs	**0.60 [0.54-0.67]**	**<0.0001**
Cataract surgery	**0.82 [0.76-0.89]**	**<0.0001**
Amount of OCTs	**1.38 [1.32-1.44]**	**<0.0001**
Costs ophthalmic encounters	**0.77 [0.76-0.78]**	**<0.0001**
Physical comorbidity	**0.87 [0.82-0.92]**	**0.001**
Hearing disorders	**1.98 [1.86-2.11]**	**<0.0001**
Mental comorbidity	**1.17 [1.10-1.23]**	**<0.0001**
Contextual characteristics		
Ophthalmic treatment setting[c]		
Specialized ophthalmic center	**0.81 [0.74-0.87]**	**<0.0001**
General hospital and specialized ophthalmic center	**1.23 [1.10-1.37]**	**<0.0001**
Not treated within ophthalmic medical specialist care	**1.59 [1.48-1.70]**	**0.0002**
Missing	0.90 [0.42-1.91]	0.78
Distance to MLVS	**0.95 [0.92-0.98]**	**0.001**
Other healthcare utilization[d]		
GP encounter	**1.23 [1.18-1.29]**	**<0.0001**
Occupational therapy	**2.32 [2.15-2.51]**	**<0.0001**
LVAs	**8.76 [7.99-9.61]**	**<0.0001**

Abbreviations: CI, confidence interval; GP, general practitioner; IVIs, intravitreal injections; MLVS, multidisciplinary low vision services; LVAs, low vision aids; OCTs, optical coherence tomography scans; OR, odds ratio.Reference group: [a]high socioeconomic status, [b]west, [c]general hospital, [d]no utilization of these types of other healthcare

*Reported p-values are corrected. Bold is significant at *p<0.002* (i.e., after correction for multiple testing with the Benjamini-Hochberg method).

Predictors for receiving multidisciplinary low vision services

As presented in Table 2, characteristics associated with higher odds for receiving multidisciplinary LVS were living in the north, east, or south compared with the west; having two or more ophthalmic diagnoses of glaucoma, diabetic retinal, retinal, and/or macular diseases versus 0 to 1 of these diagnoses; receiving more optical coherence tomography scans; having a mental comorbidity; having a comorbid hearing disorder; treatment in both a general hospital and a specialized ophthalmic center versus a general hospital only; not being treated in the ophthalmic medical specialist care versus a general hospital; general practitioner encounter; occupational therapy and LVAs.

Characteristics associated with lower odds were older age; having a low SES versus a high SES; having a physical comorbidity; treatment in a specialized ophthalmic center versus a general hospital; treatment with intravitreal injections; having had cataract surgery; higher costs for ophthalmic encounters; and greater distance to a multidisciplinary LVS center.

Internal validation

The area under the receiver operating characteristic curve of the full model adjusted for all predictors was 0.75 (95% confidence interval [CI], 0.75 to 0.76), which is considered acceptable.[25] Internal validation of the model showed a bootstrap optimism-corrected area under the receiver operating characteristic curve of 0.75 (optimism=0.0008).

Sensitivity analysis

We ran a multivariable logistic regression analysis stratified by LVAs, as data analysis showed LVAs utilization to be a strong predictor for receiving multidisciplinary LVS. The association for amount of ophthalmic diagnoses, cataract surgery, optical coherence tomography scans, physical comorbidity, hearing disorders, ophthalmic treatment setting (except for patients who were not treated within ophthalmic medical specialist care), distance to multidisciplinary LVS, and general practitioner encounter changed to non-significant for patients who utilized LVAs in 2015 to 2017 in the stratified analysis. Besides that, low vision aid users with a middle high SES had significantly lower odds for receiving multidisciplinary LVS, which was nonsignificant for LVAs nonusers and in the main analysis.

Furthermore, urban area of residence changed to significant for both, low vision aid users and nonusers. Whereas low vision aid users that lived in urban areas had higher odds for receiving multidisciplinary LVS, nonusers who lived in urban areas had lower odds for receiving multidisciplinary LVS.

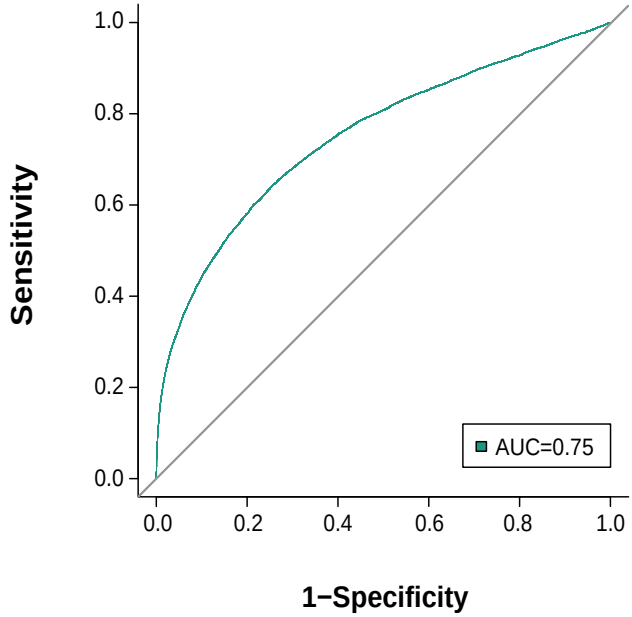

FIGURE 1. Receiver Operating Characteristic (ROC) curve presenting the discriminative power of the multivariable logistic regression model (prediction of receiving multidisciplinary LVS) to distinguish between true positives and negatives. The ROC curve is based on 97% of the data, with the remaining 3% grouped together due to having identical (model-based) outcome probabilities.

DISCUSSION

The objective of this study was to identify patient characteristics that predict receiving nonprofit multidisciplinary LVS. The strongest predictor for multidisciplinary LVS uptake was having a prescription for LVAs, followed by amount of ophthalmic diagnoses and occupational therapy. Our results furthermore indicate that patients who did not live in the west of the Netherlands, who received more optical coherence tomography scans, who were vulnerable to mental comorbidity and hearing disorders, who were treated in multiple ophthalmic treatment settings, and who had contact with their general practitioner had higher odds of receiving multidisciplinary LVS. Patients of older age, who were more socioeconomically disadvantaged, who were vulnerable to physical comorbidity, who were treated in a specialized ophthalmic center, treated with intravitreal injections, who had cataract surgery, who had higher costs for ophthalmic encounters, and who had greater distance to a multidisciplinary LVS center had a lower odds of receiving multidisciplinary LVS.

LVAs and occupational therapy were found to be strong predictors for receiving multidisciplinary LVS. In the Netherlands, LVAs are prescribed by for-profit low vision optometrists and multidisciplinary LVS organizations. We found low vision optometric services in the Netherlands in an earlier qualitative study to have a facilitating role in the referral to multidisciplinary LVS.[6] Patients may prefer to be referred to a low vision optometrist for LVAs in the first place, which in turn might lower the barrier for patients to taking the step to multidisciplinary LVS. As low vision optometrists were also found to have an important signaling function in detecting patients' multidisciplinary LVS needs,[6] this might facilitate referral as well. Our results also showed differences between low vision aid users and LVAs nonusers. Most clinical independent parameters for multidisciplinary LVS uptake changed to nonsignificant for low vision aid users, which might be explained by the facilitating role of low vision optometrists in multidisciplinary LVS access. However, patients also might have had their low vision aid prescription from a multidisciplinary LVS organization, which may explain the differences between low vision aid users and low vision aid nonusers and the strong association between LVAs and receiving multidisciplinary LVS. However, as LVAs were not defined as multidisciplinary LVS in this study and because of the absence of contextual information in the data regarding whether LVAs were provided within the context of multidisciplinary LVS or by low vision optometrists, a full explanation for the outcome of LVAs as a predictor is challenging to provide. With respect to occupational therapy, patients might feel less hampered to be referred to multidisciplinary LVS, and involved occupational therapists may already focus on the patient's (vision) disability.

Our study showed that having ocular comorbidity of combinations of glaucoma, macular, diabetic retinal, and retinal diseases was also predictive for receiving multidisciplinary LVS. There is some evidence that coexistence of glaucoma and retinal eye diseases leads to increased low vision and blindness.[26] As some international studies

found more severe vision impairment to be related to increased multidisciplinary LVS access,[10,27] this might explain our results. The administrative nature of the data might also have affected the results, because ophthalmic diagnoses might have been overcoded by ophthalmologists and therefore might have been clinically irrelevant. More research is needed to investigate the role of (having multiple) ophthalmic diagnoses and receiving multidisciplinary LVS. Although not available in our health claims data, future studies should also include visual acuity as a predictor to examine its relationship with ophthalmic diagnoses and multidisciplinary LVS access. Having multiple eye diseases may also mean contact with multiple ophthalmologists with different specializations, which may increase the odds of being referred as a patient.

While mental comorbidity predicted receiving multidisciplinary LVS, physical comorbidity significantly lowered the odds of receiving multidisciplinary LVS. In line with our results, Khimani et al.[28] found poor health status to be a barrier to multidisciplinary LVS, as did other studies.[29,30] In contrast to our findings, however, Khimani et al.[28] also found mental comorbidity, including anxiety and depression, to be a barrier. An explanation for our results might be that mental health issues may exacerbate patients' multidisciplinary LVS needs and may sooner be discussed with their healthcare provider. At the same time, providers may be more aware of patients' multidisciplinary LVS needs when their mental health is also affected, which in turn may facilitate referral.

Having a comorbid hearing disorder, which included deafness, hearing impairment and vestibular disorders in our claims data, also came forward as predictor for receiving multidisciplinary LVS. Of our study population, 9.7% were identified as having a comorbid hearing disorder, which is probably overestimated as severity of the condition could not be considered in the selection and prevalence was found to be between 0.2 and 2% in the general population.[31,32] However, having two senses affected may increase patients' difficulties in daily life and may therefore facilitate multidisciplinary LVS referral.

Being treated in 'multiple ophthalmic treatment settings' was identified as a predictor for receiving multidisciplinary LVS, which might be a proxy for the complexity of patients' eye disease and therefore may explain the facilitating role for referral to multidisciplinary LVS. As with other predictors, the chance of being referred also might be higher due to more contact with different healthcare providers. Interestingly, 39% of patients that utilized multidisciplinary LVS in 2018 did not utilize ophthalmic medical specialist care in 2015 to 2017, which indicates that they have found their way to multidisciplinary LVS, although they seem to not have been referred by their ophthalmologist in the years before. Part of these patients might have been referred before 2015 to 2018 for the first time, or in 2018 or by other medical specialists. Patients also might have entered multidisciplinary LVS by self-referral after which an official referral might have been requested from their ophthalmologist.

Furthermore, patients who were of older age, who had a low SES and who had greater distance to a multidisciplinary LVS center had lower odds of receiving multidisciplinary LVS. This is in accordance with previous work, which found older age[28] and age-related referral criteria of professionals,[6] low education,[33] low income[7], and lack of transportation[28,34] to be prohibitive factors, whereas proximity to multidisciplinary LVS[34] was found to be a facilitator. Professionals might think less about referral in older patients, assuming they are too old to benefit from multidisciplinary LVS.[6] Additionally, elderly patients might refuse multidisciplinary LVS, because of opinions that are more common in their generation,[6] such as not wanting to ask for help. Moreover, patients with a low SES might have less access due to the compulsory deductible that needs to be paid for the first 385 euros of multidisciplinary LVS. Accordingly, professionals should have extra attention for older patients, those who are socioeconomically more disadvantaged, and those who live further from a multidisciplinary LVS center away when considering referral.

Patients living in the north, east, or south of the Netherlands had higher odds of receiving multidisciplinary LVS compared with patients living in the west. This is remarkable, as most multidisciplinary LVS centers are located in the west of the country as this is the most urbanized part. More research on possible geographical disparities is needed.

Our results also revealed that treatment with intravitreal injections and having cataract surgery lowered the odds of receiving multidisciplinary LVS, which is in line with our previous qualitative study in which we found that patients with wet macular degeneration treated with intravitreal injections often refuse multidisciplinary LVS referral because of wanting to await the treatment effect.[6] Furthermore, it has been suggested that treatment with intravitreal injections and cataract surgery might lower multidisciplinary LVS needs in patients due to a positive treatment effect.[13] Higher costs for ophthalmic encounters lowered the odds for multidisciplinary LVS uptake, which might be explained by ongoing treatment of patients including diagnostic scans and thus, more contact between patients and their ophthalmologists.

We found that those who receive more diagnostic optical coherence tomography scans for diabetic retinal, retinal, and/or macular disease are more likely to receive multidisciplinary LVS, possibly due to more complexity of their eye disease.

Strengths and limitations

A strength of our study is the large sample size, which allowed for high statistical power. As the Vektis C.V. database contains health insurance data of 99% of the Dutch population (~17.5 million), we were able to include almost all multidisciplinary LVS care provided within the HIA in 2018. Accordingly, the results are highly representative. In addition, this is one of the first studies examining predictors of receiving multidisciplinary LVS with healthcare claims data in a country with full geographical and large financial coverage of multidisciplinary LVS.

Yet, our study also has some limitations. First, it reflects the Dutch situation, that is, the Dutch healthcare system and multidisciplinary LVS referral procedures. As there is great international difference regarding referral guidelines, procedures, provision, and healthcare systems, study results should be interpreted with caution in other countries.

The increased statistical power due to the large sample size might also form a limitation, as with very large sample sizes, even small effect sizes may become statistically significant.[35] To avoid drawing false conclusions of clinically irrelevant results and to diminish "the large sample size problem," we have only selected predictors that seemed relevant based on the literature, clinical expertise from the authors, and insights gained from our previous studies.

Furthermore, because of the administrative nature of the healthcare claims, certain information is missing, such as visual acuity, visual field defect, and type of ophthalmic diagnoses (International Classification of Diseases, 10th revision diagnoses). Therefore, these parameters could not be included as a predictor, although visual acuity is known to be associated with multidisciplinary LVS access.[10] With respect to the reference group, we could not select patients based on their visual acuity, which might have distorted our results. However, with the selection based on diagnoses groups known to be related to cause vision disability, we think that we were able to select patients potentially in need of multidisciplinary LVS. Our results still might have been prone to selection bias, though, as we compared a small group with all kinds of eye diseases to a large group with four eye diseases. Besides that, due to lacking information about type of diagnoses, physical and mental comorbidities were solely based on having utilized the certain types of healthcare at least once within the period of 3 years. Consequently, this might have caused bias as patients who had one-off appointments and/or minor health issues might have been classified as having comorbidity as well.

Moreover, we did not validate diagnoses for this study (internally or externally), although it is advised by best practices of research with healthcare claims in other countries to minimize the risk of undercoding, overcoding, and false identification of diagnoses.[36] Although a recent study in a cardiac population suggests that Dutch healthcare claims data are highly accurate in identifying patients with myocardial infarction,[37] a study in a nephrology population found Dutch claims data to correctly identify chronic kidney disease to vary across subgroups, that is, sensitivity was higher in younger patients and men.[38] Both these studies used external validation. To our knowledge, there are no studies that investigated validity of Dutch healthcare claims to identify ophthalmic diagnoses, and more research on this topic is warranted.

Certain subgroups of patients in this study might be underrepresented, as some patient groups might not have visited the ophthalmologists every year in the 4-year period. For example, this might be the case for patients with dry age-related macular degeneration or inherited retinal degenerations where the interval between checkup appointments may sometimes last a couple of years.

Finally, between 2015 and 2018, the second version of the referral guideline of the Dutch Society of Ophthalmology was valid (2011 to 2020). Although the referral guideline has been revised after 2020, it did not change essentially regarding visual impairment criteria, and thus, our findings are expected to be applicable to the current multidisciplinary LVS referral procedures.

In conclusion, patients who received a prescription for LVAs, occupational therapy, who had ocular comorbidity, who were more vulnerable to mental comorbidity and hearing disorders, who were treated in multiple treatment settings, and who had contact with their general practitioner were most likely to receive multidisciplinary LVS. Involved healthcare professionals may already focus on the patient's (vision) disability. Living closer to a multidisciplinary LVS center seemed to lower the barrier, which might indicate easier access. Furthermore, patients who are not seen by their ophthalmologist seem to find their way to multidisciplinary LVS anyways. Eye care practitioners should be aware, though, that, even at older age, multidisciplinary LVS can be beneficial and should have attention for those who are socioeconomically disadvantaged. A limitation of this study is the absence of visual acuity of the study population.

APPENDICES

Appendix Table A1. Selection of ophthalmic diagnoses codes for selection of the study population.

Appendix Table A2. Additional characteristics of the study population (N=574,262).

REFERENCES

1. Langelaan M, de Boer MR, van Nispen RM, Wouters B, Moll AC, van Rens GH. Impact of visual impairment on quality of life: a comparison with quality of life in the general population and with other chronic conditions. *Ophthalmic Epidemiol.* 2007;14(3):119-26.
2. Luu W, Kalloniatis M, Bartley E, Tu M, Dillon L, Zangerl B, et al. A holistic model of low vision care for improving vision-related quality of life. *Clin Exp Optom.* 2020;103(6):733-41.
3. Lim YE, Vukicevic M, Koklanis K, Boyle J. Low Vision Services in the Asia-Pacific Region: Models of Low Vision Service Delivery and Barriers to Access. *J Vis Impair Blind.* 2014;108(4):311-22.
4. van Nispen RMA, Virgili G, Hoeben M, Langelaan M, Klevering J, Keunen JEE, et al. Low vision rehabilitation for better quality of life in visually impaired adults. *Cochrane Database Syst Rev.* 2020(1).
5. World Health Organization (WHO). Universal eye health: a global action plan 2014-2019 2013 [cited 2020 Oct 3]. Available from: www.who.int/publications/i/item/universal-eye-health-a-global-action-plan-2014-2019.
6. Stolwijk ML, van Nispen RMA, van der Ham AJ, Veenman E, van Rens GHMB. Barriers and facilitators in the referral pathways to low vision services from the perspective of patients and professionals: a qualitative study. *BMC Health Serv Res.* 2023;23(1):64.
7. Lam N, Leat SJ. Reprint of: Barriers to accessing low-vision care: the patient's perspective. *Can J Ophthalmol.* 2015;50 Suppl 1:S34-9.
8. Basilious A, Basilious A, Mao A, Hutnik CML. Trends in low vision care provided by ophthalmologists in Ontario between 2009 and 2015. *Can J Ophthalmol.* 2019;54(2):229-36.
9. Khimani KS, Battle CR, Malaya L, Zaidi A, Schmitz-Brown M, Tzeng H-M, et al. Barriers to Low-Vision Rehabilitation Services for Visually Impaired Patients in a Multidisciplinary Ophthalmology Outpatient Practice. *J Ophthalmol.* 2021;2021:1-7.
10. Goldstein JE, Guo X, Boland MV, Swenor BK. Low Vision Care - Out of Site. Out of Mind. *Ophthalmic Epidemiol.* 2020;27(4):252-8.
11. Stelzer D, Graf E, Köster I, Ihle P, Günster C, Dröge P, et al. Assessing the effect of a regional integrated care model over ten years using quality indicators based on claims data – the basic statistical methodology of the INTEGRAL project. *BMC Health Serv Res.* 2022;22(1):247.
12. Tyree PT, Lind BK, Lafferty WE. Challenges of Using Medical Insurance Claims Data for Utilization Analysis. *Am J Med Qual.* 2006;21(4):269-75.
13. Stolwijk ML, van Nispen RMA, Verburg IWM, van Gerwen L, van de Brug T, van Rens GHMB. Trends in low vision service utilisation: A retrospective study based on general population healthcare claims. *Ophthalmic Physiol Opt.* 2022;42:828–38.
14. Kroneman M, Boerma W, van den Berg M, Groenewegen P, de Jong J, van Ginneken E. Netherlands: Health System Review. *Health Syst Transit.* 2016;18(2):1-240.
15. Dutch Healthcare Authority. What are our tasks? How does the Dutch healthcare system work? [cited 2023 Mar 15]. Available from: https://english.zorginstituutnederland.nl/.
16. Dutch Healthcare Authority. Monitor Zorgverzekeringen 2018 [Health Insurance Monitor 2018] 2018 [updated August 27, 2021; cited 2023 Mar 15]. Available from: https://puc.overheid.nl/nza/doc/PUC_254666_22/1/.
17. Dutch Tax and Customs Administration. Inkomensafhankelijke bijdrage Zorgverzekeringswet [Income-related contribution to the Healthcare Insurance Act] [cited 2023 Apr 7]. Available from: https://www.belastingdienst.nl/bibliotheek/handboeken/html/boeken/FISIN2018/fiscale_informatie_2018-inkomensafhankelijke_bijdrage_zorgverzekeringswet.html.

18. van Rens GHMB, Vreeken HL, van Nispen RMA. Richtlijn visusstoornissen revalidatie en verwijzing [Guideline vision disorders: rehabilitation and referral] 2011 [cited 2020 Sep 20]. Available from: http://www.vivis.nl/wp-content/uploads/2019/10/Richtlijn-visusstoornissen-revalidatie-en-verwijzing.pdf.
19. Rubin DB. Inference and missing data. *Biometrika.* 1976;63(3):581-92.
20. Lanning D, Berry D. An alternative to proc mi for large samples. An alternative to proc mi for large samples [Internet]. 2003 April 5, 2023 [cited 2023 Apr 5]. Available from: https://support.sas.com/resources/papers/proceedings/proceedings/sugi28/271-28.pdf.
21. Pregibon D. Logistic Regression Diagnostics. *Ann Stat.* 1981;9(4):705-24.
22. Benjamini Y, Hochberg Y. Controlling the false discovery rate: a practical and powerful approach to multiple testing. *J R Stat Soc Series B Stat Methodol.* 1995;57(1):289-300.
23. Austin PC, Steyerberg EW. Interpreting the concordance statistic of a logistic regression model: relation to the variance and odds ratio of a continuous explanatory variable. *BMC Med Res Methodol.* 2012;12(1):82.
24. Steyerberg EW, Harrell FE, Borsboom GJJM, Eijkemans MJC, Vergouwe Y, Habbema JDF. Internal validation of predictive models: Efficiency of some procedures for logistic regression analysis. *Journal Clin Epidemiol.* 2001;54(8):774-81.
25. Hosmer Jr DW, Lemeshow S, Sturdivant RX. Applied logistic regression: John Wiley & Sons; 2013.
26. Griffith JF, Goldberg JL. Prevalence of comorbid retinal disease in patients with glaucoma at an academic medical center. *Clin Ophthalmol.* 2015;9:1275-84.
27. Coker MA, Huisingh CE, McGwin G, Jr., Read RW, Swanson MW, Dreer LE, et al. Rehabilitation Referral for Patients With Irreversible Vision Impairment Seen in a Public Safety-Net Eye Clinic. *JAMA ophthalmology.* 2018;136(4):400-8.
28. Khimani K, Redmon C, Malaya L, Zaidi A, Schmitz-Brown M, Tzeng H-M, et al. Barriers to low vision care rehabilitation services for visually impaired patients in a multidisciplinary ophthalmology outpatient practice. *Investig Ophthalmol Vis Sci.* 2021;62(8):6122246.
29. Kaldenberg J. Low vision rehabilitation services: Perceived barriers and facilitators to access for older adults with visual impairment. *Br J Occup Ther.* 2019;82:466-74.
30. Matti AI, Pesudovs K, Daly A, Brown M, Chen CS. Access to low-vision rehabilitation services: barriers and enablers. *Clin Exp Optom.* 2011;94(2):181-6.
31. Vreeken HL, van Rens GH, Knol DL, van Reijen NA, Kramer SE, Festen JM, et al. Dual sensory loss: A major age-related increase of comorbid hearing loss and hearing aid ownership in visually impaired adults. *Geriatr Gerontol Int.* 2014;14(3):570-6.
32. Minhas R, Jaiswal A, Chan S, Trevisan J, Paramasivam A, Spruyt-Rocks R. Prevalence of Individuals With Deafblindness and Age-Related Dual-Sensory Loss. *J Vis Impair Blind.* 2022;116(1):36-47.
33. Overbury O, Wittich W. Barriers to low vision rehabilitation: the Montreal Barriers Study. *Invest Ophthalmol Vis Sci.* 2011;52(12):8933-8.
34. O'Connor PM, Mu LC, Keeffe JE. Access and utilization of a new low-vision rehabilitation service. *Clin Exp Optom.* 2008;36(6):547-52.
35. Armstrong RA. Is there a large sample size problem? *Ophthalmic Physiol Opt.* 2019;39(3):129-30.
36. Working Group for the Collection and Use of Secondary Data (AGENS) of the German Society for Social Medicine and Prevention (DGSMP) and the German Society for Epidemiology (DGEpi). Good Practice in Secondary Data Analysis (GPS) 2014 [cited 2023 Jan 20]. Available from: https://www.dgepi.de/assets/Leitlinien-und-Empfehlungen/GPS_revision2-final_august2014.pdf.

37. Eindhoven DC, van Staveren LN, van Erkelens JA, Ikkersheim DE, Cannegieter SC, Umans VAWM, et al. Nationwide claims data validated for quality assessments in acute myocardial infarction in the Netherlands. *Neth Heart J.* 2018;26(1):13-20.

38. van Oosten MJM, Brohet RM, Logtenberg SJJ, Kramer A, Dikkeschei LD, Hemmelder MH, et al. The validity of Dutch health claims data for identifying patients with chronic kidney disease: a hospital-based study in the Netherlands. *Clin Kidney J.* 2020;14(6):1586-93.

APPENDIX TABLE A1. Selection of ophthalmic diagnoses codes for selection of the study population

Diagnoses codes in claims data of the ophthalmic medical specialist care*	Diagnoses groups/diagnoses*	Selection MLVS users (Target group)	Selection MLVS nonusers (Reference group)
	No pathology		
101	No ophthalmic pathology	**X**	
102	History of pathology	**X**	
103	Risk of eye condition	**X**	
107	Systemic condition without ophthalmic pathology	**X**	
	Vision disorder / refractive error		
151	Vision disorder of unknown cause	**X**	
154	Amblyopia	**X**	
155	Refractive anomaly	**X**	
159	Other vision disorders	**X**	
	Strabismus / Binocular Function		
204	Concomitant strabismus	**X**	
205	Incomitant strabismus	**X**	
209	Other abnormalities in binocular function	**X**	
	Eyelids		
251	Acquired ptosis	**X**	
252	Congenital ptosis	**X**	
253	Blepharitis	**X**	
255	Dermatochalasis	**X**	
257	Ectropion and entropion	**X**	
258	Chalazion/stye	**X**	
259	Other eyelid pathology	**X**	
	Tear ducts		
303	Inflammation	**X**	
306	Obstruction (congenital)	**X**	
307	Obstruction (acquired)	**X**	
309	Other pathology of tear ducts	**X**	
	Orbit		
352	Graves' orbitopathy	**X**	
353	Infection / inflammation	**X**	
358	Orbital tumor	**X**	
359	Other orbit pathology	**X**	
	Conjunctiva		
402	Infectious conjunctivitis	**X**	
403	Allergic conjunctivitis	**X**	

APPENDIX TABLE A1. (continued)

Diagnoses codes in claims data of the ophthalmic medical specialist care*	Diagnoses groups/diagnoses*	Selection MLVS users (Target group)	Selection MLVS nonusers (Reference group)
404	Sicca syndrome	X	
407	Pterygium	X	
409	Other conjunctiva pathology	X	
	Cornea		
452	Keratitis	X	
454	Corneal abrasion / foreign body	X	
456	Perforation, cornea only	X	
457	Corneal dystrophy / keratoconus	X	
459	Other cornea pathology	X	
	Uvea		
502	Anterior uveitis	X	
503	Posterior uveitis / panuveitis	X	
509	Other uvea pathology	X	
	Lens		
554	Cataract	X	
557	After-cataract (Posterior Capsule Opacification)	X	
	Corpus Vitreum		
603	Endophthalmitis	X	
604	Vitreous hemorrhage	X	
607	Vitreous opacity / Vitreous detachment	X	
609	Other vitreous body pathology	X	
	Retina		
652	(chorio)Retinitis / vasculitis	X	X
654	Retinal defect / retinal detachment	X	X
655	Retinopathy (excl. DRP)	X	X
657	Vascular closure	X	X
659	Other pathologies DRP	X	X
	Macular		
704	Subretinal neovascularization	X	X
705	Maculopathy	X	X
707	Macular degeneration	X	X
709	Other pathologies macular	X	X
	Diabetic retina		
751	No diabetic retinopathy (DRP)	X	X
754	Non-proliferative DRP	X	X
755	Preproliferative DRP	X	X
757	Proliferative DRP	X	X
759	Other pathologies DRP	X	X

APPENDIX TABLE A1. (continued)

Diagnoses codes in claims data of the ophthalmic medical specialist care*	Diagnoses groups/diagnoses*	Selection MLVS users (Target group)	Selection MLVS nonusers (Reference group)
	Bulbus / sclera		
802	Episcleritis	**X**	
806	Perforation (other than corneal perforation)	**X**	
809	Other pathology of bulbus / sclera	**X**	
	Neuro-Ophthalmology		
852	Opticopathy	**X**	
854	Intracranial pathology	**X**	
859	Others neuro-ophthalmological	**X**	
	Glaucoma		
901	Glaucoma risk / ocular hypertension	**X**	**X**
904	Primary glaucoma	**X**	**X**
907	Secondary glaucoma	**X**	**X**
909	Others glaucoma	**X**	**X**
	Other		
951	No diagnosis	**X**	
954	Congenital eye anomaly not elsewhere classified	**X**	
959	Other eye abnormalities	**X**	
960	Interprofessional consultation	**X**	

Abbreviations: DRP, diabetic retinopathy; MLVS, multidisciplinary low vision services.
*Diagnoses codes relate to those used in the Netherlands for reimbursement of the ophthalmic medical specialist care. They are derived from the International Classification of Diseases, 10th revision (ICD-10) for classification, but ICD-10 codes themselves are not used in Dutch healthcare claims.

APPENDIX TABLE A2. Additional characteristics of the study population (N=574,262)

	MLVS users (n=8,766)	MLVS non users (n=565,496)	Total (N=574,262)
	n (%)	n (%)	n (%)
Sociodemographic characteristics			
Age groups			
18-29	578 (6.6)	7,011 (1.2)	7,589 (1.3)
30-39	497 (5.7)	10,334 (1.8)	10,831 (1.9)
40-49	799 (9.1)	27,156 (4.8)	27,955 (4.9)
50-59	1,306 (14.9)	67,572 (11.9)	68,878 (12.0)
60-69	1,364 (15.6)	131,822 (23.3)	133,186 (23.2)
70-79	1,635 (18.7)	186,352 (33.0)	187,987 (32.7)
80-89	1,910 (21.8)	115,823 (20.5)	117,733 (20.5)
90+	677 (7.7)	19,426 (3.4)	20,103 (3.5)
<65	3863 (44.1)	167,565 (29.6)	171,428 (29.9)
≥65	4903 (55.9)	397,931 (70.4)	402,834 (70.1)
Socioeconomic status			
Missing	70 (0.8)	3,309 (0.6)	3,379 (0.6)
Low	3,259 (37.2)	206,214 (36.5)	209,473 (36.5)
Middle	3,280 (37.4)	213,275 (37.7)	216,555 (37.7)
High	2,157 (24.6)	142,698 (25.2)	144,855 (25.2)
Area of residence			
Missing	44 (0.5)	1,419 (0.3)	1,463 (0.3)
Urban	5,911 (67.4)	393,609 (69.6)	399,520 (69.6)
Rural	2,811 (32.1)	170,468 (30.1)	173,279 (30.2)
Region of residence			
Missing	44 (0.5)	1,419 (0.3)	1,463 (0.3)
North	1,162 (13.3)	59,302 (10.5)	60,464 (10.5)
East	1,819 (20.8)	108,286 (19.1)	110,105 (19.2)
South	2,053 (23.4)	121,125 (21.4)	123,178 (21.4)
West	3,688 (42.1)	275,364 (48.7)	279,052 (48.6)
Clinical characteristics			
Ophthalmic diagnoses†			
Missing	2,294 (26.2)	0 (0)	2,294 (0.4)
0-1	5,790 (66.1)	505,822 (89.4)	511,612 (89.1)
2 or more	682 (7.8)	59,674 (10.6)	60,356 (10.5)
Ophthalmic medical specialist care			
Yes	5,315 (60.6)	486,879 (86.1)	492,194 (85.7)
No	3,451 (39.4)	78,617 (13.9)	82,068 (14.3)
IVIs†			
Yes	1,092 (12.5)	52,615 (9.3)	53,707 (9.4)
No	7,674 (87.5)	512,881 (90.7)	520,555 (90.6)
IVIs, mean (SD)‡	1.51 (5.57)	1.13 (4.74)	1.14 (4.76)

APPENDIX TABLE A2. (continued)

	MLVS users (n=8,766)	MLVS non users (n=565,496)	Total (N=574,262)
	n (%)	n (%)	n (%)
Cataract surgery‡			
Yes	820 (9.4)	76,525 (13.5)	77,345 (13.5)
No	7,946 (90.6)	488,971 (86.5)	496,917 (86.5)
Cataract surgeries, mean (SD)‡	0.13 (0.44)	0.20 (0.54)	0.20 (0.53)
OCTs, mean (SD)‡	1.80 (3.82)	1.60 (3.02)	1.60 (3.03)
Visual field tests, mean (SD)‡	0.36 (1.03)	0.58 (1.12)	0.58 (1.11)
Physical comorbidity			
Yes	6,998 (79.8)	471,097 (83.3)	478,095 (83.3)
No	1,768 (20.2)	94,399 (16.7)	96,167 (16.7)
Hearing disorders			
Yes	1,350 (15.4)	54,096 (9.6)	55,446 (9.7)
No	7,416 (84.6)	511,400 (90.4)	518,816 (90.3)
Mental comorbidity			
Yes	1,634 (18.6)	78,976 (14.0)	80,610 (14.0)
No	7,132 (81.4)	486,520 (86.0)	493,652 (86.0)
Anxiety disorders§			
Yes	85 (12.8)	4,315 (15.4)	4,400(15.4)
No	580 (87.2)	23,660 (84.6)	24,240 (84.6)
Depression§			
Yes	142 (21.4)	7,622 (27.2)	7,764 (27.1)
No	523 (78.6)	20,353 (72.8)	20,876 (72.9)
Contextual characteristics			
Type of institution‡			
Missing	7 (0.1)	678 (0.1)	685 (0.1)
No treatment in ophthalmic medical specialist care	3,451 (39.4)	78,617 (13.9)	82,068 (14.3)
Hospital	4,214 (48.1)	378,130 (66.9)	382,344 (66.6)
Independent treatment center	706 (8.1)	80,709 (14.3)	81,415 (14.2)
Hospital and independent treatment center	388 (4.4)	27,362 (4.8)	27,750 (4.8)
Distance to MLVS (km), mean (SD)	13.09 (9.48)	13.03 (9.67)	13.03 (9.7)
Missing	44 (0.5)	2,034 (0.4)	2,078 (0.4)
0-09	3,863 (44.1)	247,115 (43.7)	250,978 (43.7)
10-19	2,846 (32.5)	189,169 (33.5)	192,015 (33.4)
20-29	1,453 (16.6)	88,672 (15.7)	90,125 (15.7)
30-39	409 (4.7)	28,273 (5.0)	28,682 (5.0)
40+	151 (1.7)	10,233 (1.8)	10,384 (1.8)
Other healthcare utilization			
GP encounter			
Yes	3,800 (43.3)	208,318 (36.8)	212,118 (36.9)
No	4,966 (56.7)	357,178 (63.2)	362,144 (63.1)

APPENDIX TABLE A2. (continued)

	MLVS users (n=8,766)	MLVS non users (n=565,496)	Total (N=574,262)
	n (%)	n (%)	n (%)
Occupational therapy			
Yes	796 (9.1)	24,078 (4.3)	24,874 (4.3)
No	7,970 (90.9)	541,418 (95.7)	549,388 (95.7)
LVAs			
Yes	660 (7.5)	6,813 (1.2)	7,473 (1.3)
No	8,106 (92.5)	558,683 (98.8)	566,789 (98.7)
Healthcare costs			
MLVS, mean (SD)	1,576.64 EUR (3,296)	-	-
Ophthalmic medical specialist care encounters, mean (SD)	180.51 EUR (316.22)	290.09 EUR (297.85)	288.42 EUR (298.45)
Physical comorbidity, mean (SD)	8,062.04 EUR (18,349)	6,441.97 EUR (14,291.11)	6,466.70 EUR (14,363)
Mental comorbidity, mean (SD)	1,029.67 EUR (8,778)	543.77 EUR (5,353.93)	551.19 EUR (5,423)
GP care encounters, mean (SD)	89.41 EUR (223.72)	62.03 EUR (149.17)	62.45 EUR (150.62)
LVAs, mean (SD)	112.77 EUR (768.857)	13.50 EUR (178.48)	15.10 EUR (201.34)

Data are n/n (%) or n/N (%), unless otherwise specified.
Abbreviations: IVIs, intravitreal injections; GP care, general practitioner care; LVAs, low vision aids; MLVS, multidisciplinary low vision services; SD, standard deviation; OCTs, optical coherence tomography-scans.
† Within ophthalmic medical specialist care based on the years 2015-2018. Amount of ophthalmic diagnoses of glaucoma, diabetic retinal, retinal and/or macular diseases. Having 0 ophthalmic diseases means that patients did not have one of these four diagnoses, but had another diagnosis. This only applies to the MLVS users, as the reference group was selected based on the four diagnoses.
‡ MLVS patients were treated within the ophthalmic medical specialists care.
§ Data are n/665 (%) for MLVS users, n/27,975 (%) for MLVS nonusers and n/28,640 (%) for total of patients treated within specialized mental healthcare. Patients could have been treated for both, anxiety and depression.

CHAPTER 5

A retrospective big data study using healthcare insurance claims to investigate the role of comorbidities in receiving low vision services

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Frontiers in Health Services. 2024;4:1264838.
doi: 10.3389/frhs.2024.1264838

ABSTRACT

Introduction

The aim was to examine the association between physical and mental comorbidity with receiving multidisciplinary low vision services (LVS).

Methods

A retrospective study based on Dutch claims data of health insurers was performed. We retrieved data (2015-2018) of patients (≥18 years) with eye diseases causing severe vision loss who received multidisciplinary LVS at Dutch rehabilitation organizations in 2018 (target group) and patients who did not receive multidisciplinary LVS, but who received ophthalmic medical specialist care for glaucoma, macular, diabetic retinal and/or retinal diseases in 2018 (reference group). For examining the association between the patients' comorbidities and receiving multidisciplinary LVS, multivariable logistic regression was used. The relative quality of five different models was assessed with the Akaike Information Criterion (AIC).

Results

The study population consisted of 574,262 patients, of which 8,766 in the target group and 565,496 in the reference group. Physical comorbidity was found in 83% and 14% had mental comorbidity. After adjustment for all assumed confounders, both physical and mental comorbidity remained significantly associated with receiving multidisciplinary LVS. In the adjusted model, which also included both comorbidity variables, the best relative quality was found to describe the association between mental and physical comorbidity and receiving multidisciplinary LVS.

Conclusions

Mental comorbidity seemed to be independently associated with receiving multidisciplinary LVS, implying that the odds for receiving a multidisciplinary LVS referral are higher in patients who are vulnerable to mental comorbidity. Physical comorbidity was independently associated, however, the association with receiving multidisciplinary LVS might not be that meaningful in terms of policy implications. Providing mental healthcare interventions for people with VI seems warranted.

INTRODUCTION

Low vision services (LVS) are essential in eye care. Through different kind of training and support, such as training in the use of low vision aids (LVAs), computer training, orientation and mobility training, and psychological support they offer people with a visual impairment the opportunity to participate in society and regain or maintain independence, contributing to a better quality of life.

Despite the relevance of LVS, research has repeatedly shown that access is jeopardized by barriers in the referral pathways towards LVS. However, the role of comorbidities of people with visual impairment in receiving LVS is not fully understood. Although in some studies physical comorbidity or poorer health status has been identified as a barrier for LVS access,[1-3] this has not been confirmed in other studies.[4] In turn, it has been suggested that a great amount of people with visual impairment utilizing LVS experience anxiety and/or depression,[5] but in another study a hindering role of mental comorbidity in receiving LVS has been reported.[6] Differences in study outcomes may be explained by study design and limitations in data analysis.

The aim of this study was to examine the association between physical comorbidity and mental comorbidity and receiving multidisciplinary LVS, respectively, while accounting for potential confounders. As this will be the first study, to our knowledge, that examines the relationship between comorbidities and receiving multidisciplinary LVS based on population-based healthcare claims data in a high-income country where LVS is fully funded and provided nationwide, we expect to find results that are specific for this healthcare context. Insights may be valuable for policy makers and healthcare providers to diminish barriers for vulnerable subgroups of people with visual impairment in the referral pathways to multidisciplinary LVS. This, in turn, ensures that more people in need receive the care they require.

METHODS

Administrative healthcare claims data between 2015 and 2018 were used of patients ≥18 years with eye diseases that cause severe vision loss who received care in Dutch outpatient multidisciplinary LVS in 2018 (n=8,766) and patients who did not receive multidisciplinary LVS, but ophthalmic medical specialist care for glaucoma, macular, diabetic retinal, and/or retinal diseases in 2018 (n=565,496). For both groups, patients who received multidisciplinary LVS in 2015-2017 and thus, before 2018, were excluded to allow examination of the association with comorbidity and first time receipt of multidisciplinary LVS in the four-year period. The data related to healthcare provided within the Dutch Health Insurance Act and was retrieved from Vektis C.V., a healthcare information center which routinely collects claims data of all Dutch health insurers.[7]

The dependent variable was multidisciplinary LVS utilization, which was defined as having received multidisciplinary LVS at least once in 2018. Physical comorbidity was based on medical specialist care other than ophthalmology in 2015-2017, which was available as total costs per patient per medical specialty for each of the three years. Medical specialties related to diseases of the respiratory system, musculoskeletal system, cardiovascular system, skin and subcutaneous tissue, digestive system, urogenital system, other disorders of the nervous system and senses, endocrine/nutritional/metabolic diseases, epilepsy, hearing disorders/inner ear, multiple sclerosis, Parkinson's disease, allergies, infectious diseases, injury, neoplasms, and diseases of the blood and blood-forming organs. Having physical comorbidity was defined as having at least one cost registration within at least one of these medical specialties between 2015-2017. Mental comorbidity was based on the type of mental healthcare facility in which someone had been treated, encompassing basic and specialized mental healthcare, psychological care provided by general practice specialized mental healthcare nurses and other psychological care. It was also available as reimbursed costs per year per person. Mental comorbidity was defined as having at least one cost registration between 2015-2017. Based on relevance and availability, age, sex, socioeconomic status (SES), area of residence and amount of ophthalmic diagnoses, were retrieved from the claims data and modeled as confounders. SES was defined as low, middle or high SES, and area of residence was categorized as urban and rural area of residence. Amount of ophthalmic diseases was determined by the amount of different diagnoses (glaucoma, macular, diabetic retinal, retinal, and/or other eye diseases), with the categorization into 0-1 diagnoses and 2 or more diagnoses.

We used multivariable logistic regression for examining the association between the patients' comorbidities and receiving multidisciplinary LVS. Both the dependent variable (multidisciplinary LVS utilization) and the determinants (comorbidities) were dichotomous. The potential confounders were selected according to the "disjunctive cause criterion", as proposed by VanderWeele and Shpitser[8] whereby variables are classified as confounders if they can be considered causes of the determinant, the dependent variable or both.

There were missing data for SES, area of residence and amount of ophthalmic diagnoses, which were assumed to be missing at random (MAR) and imputed according to Lanning and Berry.[9] Furthermore, assumptions for logistic regression were tested, after which age was log transformed.[10] We tested two crude models that only considered the association between the comorbidities and receiving multidisciplinary LVS, and three models that included potential confounders. To identify the model with the best relative quality, we calculated the Akaike Information Criterion (AIC) for each model.[11]

Data for this study was pseudonymized and aggregated to a minimum subgroup level of n>10 to guarantee confidentially of individual patient's and care provider's information.[12] The Medical Ethics Committee of Amsterdam University Medical Centers, location VUmc approved the study protocol.

RESULTS

Of the entire study population (N=574,262), 83% had physical comorbidity (79.8% multidisciplinary LVS users vs. 83.3% multidisciplinary LVS nonusers) and 14% had mental comorbidity (18.6% multidisciplinary LVS users vs. 14.0% multidisciplinary LVS nonusers) (Table 1).

In the crude models (1 and 2), both physical and mental comorbidity were significantly associated with receiving multidisciplinary LVS (Table 2). Where physical comorbidity was negatively associated with receiving multidisciplinary LVS, mental comorbidity was positively associated. After adjustment for confounders in model 3, 4 and 5, both determinants remained significantly associated with receiving multidisciplinary LVS. However, there was a slight decrease in the estimates.

Model 5 had the best relative quality to describe the association between mental and physical comorbidity and receiving multidisciplinary LVS, respectively. After adjusting for assumed confounders, patients with physical comorbidity had a 0.84 lower odds of receiving multidisciplinary LVS compared to patients without physical comorbidity. Patients with a mental comorbidity had a 1.29 higher odds of receiving multidisciplinary LVS compared to patients with no mental comorbidity.

TABLE 1. Characteristics of the study population (N=574,262)

	Multidisciplinary LVS users n=8,766	Multidisciplinary LVS nonusers n=565,496	Total N=574,262
	n (%)	n (%)	N (%)
Sex, female	4,636 (52.9)	303,354 (53.6)	307,990 (53.6)
Age, y, range 18-106, mean (SD)	65.27 (19.61)	69.68 (13.38)	69.61 (13.51)
Age groups			
18-29	578 (6.6)	7,011 (1.2)	7,589 (1.3)
30-39	497 (5.7)	10,334 (1.8)	10,831 (1.9)
40-49	799 (9.1)	27,156 (4.8)	27,955 (4.9)
50-59	1,306 (14.9)	67,572 (11.9)	68,878 (12)
60-69	1,364 (15.6)	131,822 (23.3)	133,186 (23.2)
70-79	1,635 (18.7)	186,352 (33.0)	187,987 (32.7)
80-89	1,910 (21.8)	115,823 (20.5)	117,733 (20.5)
90+	677 (7.7)	19,426 (3.7)	20,103 (3.5)
<65	3,863 (44.1)	167,565 (29.6)	171,428 (29.9)
≥65	4,903 (55.9)	397,931 (70.4)	402,834 (70.1)
Socioeconomic status			
Missing	70 (0.8)	3,309 (0.6)	3,379 (0.6)
Low	3,259 (37.2)	206,214 (36.5)	209,473 (36.5)
Middle	3,280 (37.4)	213,275 (37.7)	216,555 (37.7)
High	2,157 (24.6)	142,698 (25.2)	144,855 (25.2)
Area of residence			
Missing	44 (0.5)	1,419 (0.3)	1,463 (0.3)
Urban	5,911 (67.4)	393,609 (69.6)	399,520 (69.6)
Rural	2,811 (32.1)	170,468 (30.1)	173,279 (30.2)
Amount of ophthalmic diagnoses[a]			
Missing	2,294 (26.2)	0 (0)	2,294 (0.4)
0-1	5,790 (66.1)	505,822 (89.4)	511,612 (89.1)
2 or more	682 (7.8)	59,674 (10.6)	60,356 (10.5)
Physical comorbidity			
Yes	6,998 (79.8)	471,097 (83.3)	478,095 (83.3)
No	1,768 (20.2)	94,399 (16.7)	96,167 (16.7)
Mental comorbidity			
Yes	1,634 (18.6)	78,976 (14.0)	80,610 (14.0)
No	7,132 (81.4)	486,520 (86.0)	493,652 (86.0)

Data are n/n (%) or n/N (%). Abbreviations: SD, standard deviation; LVS, low vision services.
[a]Within ophthalmic medical specialist care based on the years 2015-2018. Amount of ophthalmic diagnoses of glaucoma, (diabetic) retinal or macular diseases. Having 0 ophthalmic diseases means that patients did not have one of these four diagnoses, but had another diagnosis. This only applies to the multidisciplinary LVS users, as the reference group was selected based on the four diagnoses.

TABLE 2. Association between mental and physical comorbidity and receiving multidisciplinary LVS

Independent variables	Model 1[b]		Model 2[b]		Model 3[c]		Model 4[c]		Model 5[d]	
	OR [95%]	p*	OR [95%]	p*	OR [95%]	p*	OR [95%]	p*	OR [95%]	p*
Physical comorbidity	**0.79 [0.75-0.84]**	**<.0001**			**0.86 [0.81-0.90]**	**<.0001**			**0.84 [0.80-0.89]**	**<.0001**
Mental comorbidity			**1.41 [1.34-1.49]**	**<.0001**			**1.27 [1.20-1.34]**	**<.0001**	**1.29 [1.22-1.37]**	**<.0001**
AIC	90652.749		90579.690		88443.363		88404.145		88366.811	

Abbreviations: OR, odds ratio; AIC, Akaike Information Criterion*Bold is significant at *p<0.05*

[b]Unadjusted analyses.

[c]Adjusted for sex (male, female), age (continuous), socioeconomic status (low, middle, high), area of residence (rural, urban) and amount of ophthalmic diagnoses (0-1, 2 or more).

[d]Adjusted for sex (male, female), age (continuous), socioeconomic status (low, middle, high), area of residence (rural, urban) and amount of ophthalmic diagnoses (0-1, 2 or more) and leaving both determinants physical and mental comorbidity in the model.

DISCUSSION

Our study showed that both, having mental comorbidity and physical comorbidity were independently associated with receiving multidisciplinary LVS after adjusting for confounding factors.

Patients with a mental comorbidity had a 1.29 higher odds of receiving multidisciplinary LVS compared to patients with no mental comorbidity, which contradicts earlier study results.[6] Findings indicate that patients who are more vulnerable to mental comorbidity and who had mental complaints severe enough to warrant mental healthcare, have a greater chance of receiving multidisciplinary LVS. Mental comorbidity may amplify patients' multidisciplinary LVS needs and stimulate patients to discuss them with their provider, which in turn might facilitate referral to multidisciplinary LVS. Mental comorbidity of patients might also be a trigger for referring healthcare providers, such as ophthalmologists and optometrists, to be more aware. However, multidisciplinary LVS may not be necessarily provided for mental complaints but could also be given for practical support. Previous research found a prevalence of 32% of subthreshold depression and a prevalence of 16% of subthreshold anxiety in a LVS population of older adults (aged ≥60 years) in the Netherlands and Flanders (the Dutch speaking part of Belgium).[13] Another meta-analysis, which included studies from around the world, found a prevalence of approximately 25% of depression in patients with visual impairment of eye clinics and low vision rehabilitation services. The majority of these patients were 65 years or older.[14] These numbers differ from our study, where we found that 19% of the multidisciplinary LVS users had mental comorbidity. Since our study does not provide insight into patients who had mental complaints but did not receive mental healthcare, and included patients who were 18 years or older who could have various mental disorders, it is very likely that mental comorbidity in our study is underestimated. This indicates that a substantial number of patients do not receive mental healthcare, which stresses the importance for providing mental health interventions for people with VI. Literature further suggests that mental health complaints may be underdetected by eye care providers, such as ophthalmologists and optometrists.[15,16] Our findings imply that providers should be aware of mental comorbidity in patients, so that those in need of psychological support can receive that care.

Furthermore, patients with physical comorbidity had a 0.84 lower odds of receiving multidisciplinary LVS compared to patients with no physical comorbidity. This is in line with previous literature.[1,2,6] A possible explanation could be that patients with physical comorbidity may refuse referral, because of prioritizing other physical health problems and treatments. As a result, their multidisciplinary LVS needs may be demoted to a secondary concern. Physical comorbidity might also affect patients' mobility and thus, multidisciplinary LVS access. It should be noted however, that the vast majority of the study population had physical comorbidity, which might be explained by the fact that

we selected a population that is more vulnerable to physical comorbidity by definition. Therefore, this determinant might not be that meaningful in terms of policy implications.

A strength of our study is the large sample size, which increases statistical power, and the use of population-based healthcare claims data of almost all Dutch citizens (99% of 17.2 million in 2018), which increases generalizability. Furthermore, to our knowledge, this is the first study on the association between physical and mental comorbidity with receiving multidisciplinary LVS.

However, healthcare claims data are not initially intended for scientific purposes. In our study, valuable information about visual acuity, visual field defects and severity of the visual impairment was unavailable, whereas earlier severity was found to be strongly related with receiving LVS.[17]

Furthermore, we could not differentiate between specific types of mental diagnoses, because this information was not available in the data. It would have been interesting to get more insight into which mental comorbidities exactly are associated with receiving multidisciplinary LVS as this information is missing from literature. Furthermore, in another qualitative study on LVS access, mental comorbidity, which was identified as a barrier, included anxiety and/or depression.[6] Our study included all types of mental diagnoses and study results therefore might differ. The fact that comorbidity could also be based on one-off appointments as it was defined having utilized the certain types of healthcare at least once within the period of three years, might have limited our results as well. Consequently, the 83% of patients having physical comorbidity might have been an overestimation.

Besides that, our results might have been affected by coding errors as this is a common bias in administrative claims data.[18] This may have introduced selection bias, possibly affecting generalizability of our results. There are contradicting results regarding validity of Dutch healthcare claims data and validity studies on Dutch ophthalmic healthcare claims data are missing.[19,20]

Moreover, although we described a large group of patients who received multidisciplinary LVS (n=8,766), it was relatively small compared to the reference group (n=565,496). We may have introduced selection bias by comparing this relatively small group of patients with all kinds of eye diseases with a large group with a selection of eye diseases that are most likely to cause visual impairment.

Lastly, our results may not be generalizable to other countries with other healthcare systems and LVS referral procedures.

Our findings demonstrate that mental comorbidity has an independent positive association with receiving multidisciplinary LVS. This indicates that that the odds for receiving a multidisciplinary LVS referral are higher in patients who are vulnerable to mental comorbidity, hence, having mental comorbidity seems to be a facilitator in the referral pathway towards multidisciplinary LVS. Physical comorbidity seemed to be negatively associated with receiving multidisciplinary LVS, however this association might

not be that meaningful for policy makers as the majority of the study population had physical comorbidity and we selected a population that is more vulnerable to physical comorbidity by definition. Future research should investigate the influence of other potential confounders. Finally, as it is likely that the prevalence of mental comorbidity in our study is underestimated, researchers and policy makers should be aware of mental complaints in patients and focus on providing mental healthcare interventions for people with visual impairment.

REFERENCES

1. Matti AI, Pesudovs K, Daly A, Brown M, Chen CS. Access to low-vision rehabilitation services: barriers and enablers. *Clin Exp Optom.* 2011;94(2):181-6.
2. O'Connor PM, Mu LC, Keeffe JE. Access and utilization of a new low-vision rehabilitation service. *Clin Exp Optom.* 2008;36(6):547-52.
3. Khimani KS, Battle CR, Malaya L, Zaidi A, Schmitz-Brown M, Tzeng H-M, et al. Barriers to Low-Vision Rehabilitation Services for Visually Impaired Patients in a Multidisciplinary Ophthalmology Outpatient Practice. *J Ophthalmol.* 2021;2021:1-7.
4. Mwilambwe A, Wittich W, Freeman EE. Disparities in awareness and use of low-vision rehabilitation. *Can J Ophthalmol.* 2009;44(6):686-91.
5. van der Aa HP, Krijnen-de Bruin E, van Rens GH, Twisk JW, van Nispen RM. Watchful waiting for subthreshold depression and anxiety in visually impaired older adults. *Qual Life Res.* 2015;24(12):2885-93.
6. Khimani K, Redmon C, Malaya L, Zaidi A, Schmitz-Brown M, Tzeng H-M, et al. Barriers to low vision care rehabilitation services for visually impaired patients in a multidisciplinary ophthalmology outpatient practice. *Investig Ophthalmol Vis Sci.* 2021;62(8):6122246.
7. Vektis. Datawarehouse n.d. [cited 2019 December 10]. Available from: https://www.vektis.nl/over-vektis/datawarehouse.
8. VanderWeele TJ, Shpitser I. A New Criterion for Confounder Selection. *Biometrics.* 2011;67(4):1406-13.
9. Lanning D, Berry D. An alternative to proc mi for large samples. An alternative to proc mi for large samples [Internet]. 2003 April 5, 2023 [cited 2023 Apr 5]. Available from: https://support.sas.com/resources/papers/proceedings/proceedings/sugi28/271-28.pdf.
10. Rubin DB. Inference and missing data. *Biometrika.* 1976;63(3):581-92.
11. Bozdogan H. Model selection and Akaike's Information Criterion (AIC): The general theory and its analytical extensions. *Psychometrika.* 1987;52(3):345-70.
12. Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation), OJ 2016 L 119/1.
13. van der Aa HPA, Comijs HC, Penninx BWJH, van Rens GHMB, van Nispen RMA. Major Depressive and Anxiety Disorders in Visually Impaired Older Adults. *Invest Ophthalmol Vis Sci* 2015;56(2):849-54.
14. Parravano M, Petri D, Maurutto E, Lucenteforte E, Menchini F, Lanzetta P, et al. Association Between Visual Impairment and Depression in Patients Attending Eye Clinics: A Meta-analysis. *JAMA Ophthalmol.* 2021;139(7):753-61.
15. Nollett CL, Bray N, Bunce C, Casten RJ, Edwards RT, Hegel MT, et al. High Prevalence of Untreated Depression in Patients Accessing Low-Vision Services. *Ophthalmology.* 2016;123(2):440-1.
16. van Munster EPJ, van der Aa HPA, Verstraten P, Heymans MW, van Nispen RMA. Improved intention, self-efficacy and social influence in the workspace may help low vision service workers to discuss depression and anxiety with visually impaired and blind adults. *BMC Health Serv Res.* 2022;22(1):528.
17. Goldstein JE, Guo X, Boland MV, Swenor BK. Low Vision Care - Out of Site. Out of Mind. *Ophthalmic Epidemiol.* 2020;27(4):252-8.
18. Stein JD, Lum F, Lee PP, Rich WL, 3rd, Coleman AL. Use of health care claims data to study patients with ophthalmologic conditions. *Ophthalmology.* 2014;121(5):1134-41.

19. Eindhoven DC, van Staveren LN, van Erkelens JA, Ikkersheim DE, Cannegieter SC, Umans VAWM, et al. Nationwide claims data validated for quality assessments in acute myocardial infarction in the Netherlands. *Neth Heart J.* 2018;26(1):13-20.
20. van Oosten MJM, Brohet RM, Logtenberg SJJ, Kramer A, Dikkeschei LD, Hemmelder MH, et al. The validity of Dutch health claims data for identifying patients with chronic kidney disease: a hospital-based study in the Netherlands. *Clin Kidney J.* 2020;14(6):1586-93.

CHAPTER 6

Low vision aids provision in an urban setting in Germany between 2014 and 2017: a regional population based study with healthcare claims data

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Graefe's Archive for Clinical and Experimental
Ophthalmology. 2024.
doi:10.1007/s00417-024-06541-7

ABSTRACT

Purpose

Little is known about the utilization of low vision services (LVS) in Germany. To understand which persons and how often these services would be utilized, this study aimed to investigate low vision aids (LVAs) provision in an urban setting and to describe user characteristics and trends in their characteristics.

Methods

A retrospective study based on a population-based healthcare claims database in Cologne (N=~500,000), Germany. The study population comprised individuals, who were continuously insured at four large statutory health insurers and who redeemed a prescription for visual aids or aids for blindness between January 2014 and December 2017. We examined their sociodemographic and clinical characteristics. Trends in characteristics were examined with logistic and linear regression models over time.

Results

Out of ~500,000 persons, 781 unique individuals (~0.2%) redeemed an LVA prescription. They were mainly female (68.7%), 60 years or older (75.3%) and had macular degeneration (50.6%) and/or glaucoma (25.9%). In the working-age subgroup, 33.8% were employed. Visual aids were most often prescribed (74.1%) and of all types of LVAs, individuals most commonly redeemed a prescription for magnifiers (35.8%), screen readers (34.3%) and/or canes (17.1%). Of the entire study population, 75.4% received their prescription from an ophthalmologist, 5.3% from a general practitioner (GP) and 7.1% from other medical specialists. Significant trends in characteristics of individuals who redeemed an LVA prescription were not found.

Conclusions

Between 2014 and 2017, 781 individuals in Cologne redeemed an LVA prescription. They had characteristics which can be mostly explained by the epidemiology of visual impairment. Results indicate that individuals that redeemed LVAs have a magnification requirement of ≥1.5-fold and ≥6-fold. Furthermore, next to ophthalmologists, GPs and other medical specialists seem to play a role in LVA provision as well, which should be taken into account by policy makers when planning interventions for increasing LVS provision. Our findings provide a starting point to examine LVS provision in Germany.

INTRODUCTION

The most impactful consequence of ophthalmic diseases is visual impairment, which is defined as low vision or blindness and is characterized by an irreversible loss of sight.[1] Visual impairment challenges the quality of life, due to impaired participation in daily life, increased risk of psychological distress, especially anxiety and depression, and increased risk of falls and fractures.[2-5] In addition, visual impairment has a huge economic burden due to high healthcare costs and productivity losses.[6]

In Germany, which has over 84 million inhabitants, between 500,000 and 1 million people are estimated to be visually impaired, of which the majority is caused by macular degeneration, glaucoma and diabetic retinopathy.[7-10] Most people affected are 60 years or older and with an ageing population, prevalence is expected to rise rapidly in the next decades.[11] Given this fact and its tremendous negative consequences, visual impairment forms a great threat for public health and society.

Low vision services (LVS) are important to counteract this negative impact, as they have shown to be effective in improving quality of life and to be cost-effective from a societal perspective[12] LVS in Germany are wide-ranging, from low vision aids (LVAs) prescription and training (e.g., magnifiers, electronic reading devices), to support and training in activities of daily living (e.g., cooking, dressing), training in mobility and orientation (e.g., walking with cane), and psychological therapy.[13-15] They teach individuals to compensate for their visual impairment and to gain (back) independence.

LVS in Germany are offered in segmented form by different (healthcare) institutions, e.g., ophthalmology departments in hospitals/eye clinics or other medical practices, optician practices, social services/social work institutions and patient organizations. Professionals involved are ophthalmologists, opticians, specialized teachers for visually impaired, psychologists, but also volunteers of local patient organizations and other local societies for the visually impaired.[13,16,17] They are (partially) paid by health, retirement and accident insurance, by other integration assistance benefits for people with disabilities paid by the German government, or are free of charge as they are offered by local patient or charity organizations.[13,18] Sometimes, however, patients must pay for it themselves.

Despite the available LVS facilities and the relevance of these services, there are only a few studies on LVS provision in Germany. International studies have shown that LVS delivery can be hampered by barriers, such as lack of referral by eye care professionals, distance to LVS and healthcare costs for services, leading to limited access for people who are in need of LVS and to inefficiency of service provision.[19-24] This could also be the case for Germany, but with the scarcity of research on LVS provision, little can be said about the adequacy of these services in this high-income country.

In the past two decades, there is a growing body of research that uses healthcare claims data to get insight into delivery of care and healthcare planning.[25,26] With regard to LVS, recent studies have shown that population-based studies with healthcare claims

data in countries where LVS is (partially) paid by health insurance, are valuable in gaining insight into trends in LVS utilization, characteristics of LVS users and possible barriers and facilitators.[27] Stolwijk et al.[28] found that LVS utilization had decreased in the Netherlands between 2015 and 2018, but showed an increase in certain LVS user characteristics such as physical comorbidity and utilization of LVAs. Basilious et al.[27] conducted a regional study in Canada and found an increase of LVS utilization since 2009. However, barriers in service access were found with regard to age, sex and geographic location.

Against this background, this study provides an exploration of LVS provision and characteristics of LVS users in an urban setting in Germany based on regional healthcare claims data of the city of Cologne, North Rhine-Westphalia. LVS, which are (partially) funded by health insurance, comprise of LVAs, occupational therapy and psychological therapy. As these therapies can also be provided outside the context of LVS, this study focuses on LVAs. The aim of the study was to investigate how many people received an LVA prescription and what kind of LVAs were prescribed between 2014 and 2017 in Cologne. In addition, we aimed to study sociodemographic- and clinical characteristics of individuals with an LVA prescription and trends in these characteristics in this period.

METHODS

Design

We conducted a retrospective study based on a regional population-based healthcare claims database in Germany. The study was conducted in accordance with the 'Good Epidemiological Practice' by Hoffmann et al.[29] and the 'Good Practice of Secondary Data Analysis' by the Working Group for the Collection and Use of Secondary Data (AGENS) of the German Society for Social Medicine and Prevention (DGSMP) and the German Society for Epidemiology (DGEpi).[30]

The German health insurance system

Healthcare in Germany is paid by statutory and private health insurance (SHI, PHI).[31,32] The SHI is mandatory for all German citizens who have a gross annual income of less than 64,350 EUR (2022). Besides that, citizens who receive government benefits, e.g., employment benefit recipients, students, retired citizens, citizens who applied for pension, and certain family members are also insured by SHI. Citizens with a higher annual income can opt for PHI instead of SHI, but do not have to. This also applies to self-employees, freelancers, civil servants and some other groups. Both the SHI and the PHI charge 14.6% of the gross salary, which is equally shared between employer and employee. Furthermore, each health insurance charges an additional contribution to its members, which varies between 0.3% and 1.8% of the gross salary of the insured. Before 2021, citizens could switch insurance every 18 months, which was changed to 12 months after 2021.

Approximately 87% of German citizens are insured by SHI and around 11% have PHI. Among other benefits, the SHI covers treatment for disease, including inpatient and outpatient care, psychotherapy, dental care, nursing care at home, medical aids, socio-therapy and certain types of rehabilitative care.

Data source

The healthcare claims data were requested from the Cologne Research and Development Network (CoRe-Net).[33] The database contains data of the SHI of four big German health insurers (AOK Rheinland/Hamburg, BARMER Ersatzkrankenkasse (BARMER), DAK-Gesundheit (DAK) and pronova Betriebskrankenkassen (pronova-BKK)), including data of approximately 500,000 insured inhabitants of Cologne (~1 million) per year between 2014 and 2017.

Study population

Low vision aids

In Germany, medical aids are generally covered if they are included in the list of medical aids by The Federal Joint Committee of Germany.[34] This list includes various product groups, to which available medical aids on the market are allocated with an individual product

code. This study focused on LVAs that belong to product group '07' (aids for blindness) and '25' (visual aids). Our study focuses on 2014-2017 data. According to the medical aids list, insured individuals who were legally blind or who had severe visual impairment according to following definitions were eligible for funding of aids for blindness by health insurance in this period:

I. *Blind:* best corrected visual acuity of ≤0.02 in the better eye or an equivalent disturbance of vision (for example due to visual field loss);
II. *Severe visual impairment:* best corrected visual acuity of ≤0.05 but >0.02 in the better eye or an equivalent disturbance of visual function. This applies when the impairment of vision results in a disability rating (GdS) of 100 according to the German law (§30 BVG) and blindness has not yet occurred.

Furthermore, the medical aids regulation of the German National Association of Statutory Health Insurance Funds defines which medical aids, among which visual aids, are covered by the SHI.[35] This study refers to the regulation that was valid between 2014 and 2017.[36-38] According to this regulation, for people younger than 18 years old, all visual aids were funded. For people aged 18 years or older, visual aids were funded if they met following criterion:

I. *Visual impairment:* best corrected visual acuity of ≤0.30 or a binocular visual field of ≤10° around the central fixation point.

According to the medical aids regulation, visual aids need to be prescribed by an ophthalmologist. Aids for blindness can be prescribed by any medical specialist. This also applied to the 2014-2017 regulations.

Sample selection

Figure 1 shows the results of the sample selection procedure. In this study, when we mention individuals who received a prescription or who received LVAs, we are referring to those who actually redeemed visual aids/aids for blindness/LVAs after receiving a prescription. Healthcare claims data of all insured individuals within the CoRe-Net database who received a prescription for visual aids and/or aids for blindness within the selected product groups at least once between the 1st of January 2014 until the 31st of December 2017 were requested for this study. This resulted in a CoRe-Net baseline dataset of n=16,342.

For our research questions we selected those who actually received LVAs. Individuals who only received aids prescribed from the product group 'visual aids' not sufficient for people with visual impairment, were excluded. These were individuals who received glasses and lenses, which are mainly prescribed for refractive error and astigmatism and

therefore assumed not to be visually impaired by definition. This led to a sample size of n=2,079.

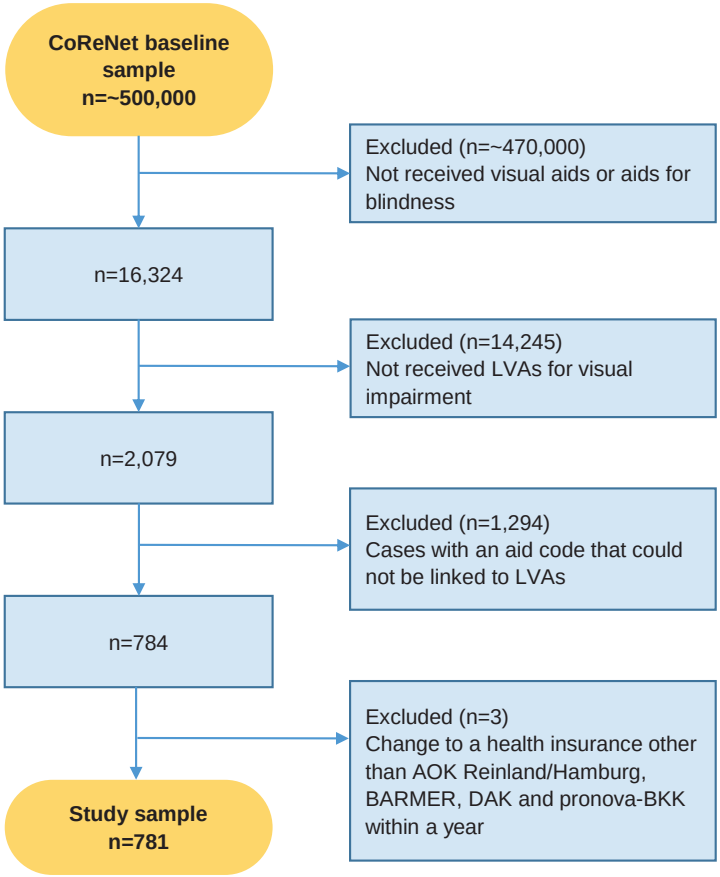

FIGURE 1. Flowchart of the study sample selection procedure.
Abbreviations: LVAs, low vision aids.

Plausibility checks were done to retrieve false information in the claims data regarding the product codes within the selected product groups.[29] Of the 182 distinct product codes occurring in the dataset (n=2,079), 44 codes could not be linked to the selected LVAs from the medical aids list. Of those, 26 were identified as pharmaceutical numbers and as not related to LVAs. For the remaining 18 missing codes, further plausibility checks were done to see if they could be linked to LVAs. For every year, we examined whether the prescriptions for these missing product codes were done by ophthalmologists and/or whether individuals with such a prescription were treated for ophthalmic diagnoses and/or with ophthalmic

procedures within the inpatient care. For a missing product code to be considered as an LVA, we set following criterion: the prescription was done by an ophthalmologist and individuals with a prescription either had been treated for an ophthalmic disease leading to visual impairment or had received an ophthalmic procedure. Specialist codes, codes of the International Classification of Diseases, 10th revision, German modification (ICD-10-GM codes) and medical procedure codes (German Uniform Assessment Standard, EBM) from the outpatient care within the data were used for this examination.

Eight out of the 18 remaining missing product codes were considered as LVAs, the other 10 remained missing for unknown reasons. All 36 missing product codes were excluded from the dataset, resulting in a remaining sample size of n=784.

Furthermore, only continuously SHI insured individuals were included per year. More specifically, those who changed to an insurer other than the four included in the CoRe-Net were excluded from the dataset. The final study sample included 781 distinct individuals. The dataset contained individual annual sociodemographic data, including year of birth, sex, postal code, working status and death, as well as individual clinical data, including inpatient and outpatient patient history, containing ICD-10-GM diagnoses and clinical procedures.

LVA prescriptions

We investigated the annual LVA prescriptions of the study population, the type of LVAs that were prescribed and the prescribing medical specialists of LVAs.

Sociodemographic characteristics

The annual age and sex distribution, as well as working status of individuals who received LVAs were retrieved from the healthcare claims. We investigated whether individuals had an occupation or not in the year of their LVA prescription.

Clinical characteristics

Clinical characteristics were investigated by looking at ophthalmic diagnoses, physical comorbidity and mental comorbidity based on ICD-10-GM codes from the inpatient and outpatient care. In Germany, outpatient care is most often provided outside the hospital in specialized medical care practices, such as ophthalmology clinics and general practitioner (GP) practices, whereas inpatient care is offered at hospitals.

We examined treatment prevalence of ophthalmic diagnoses in a stepwise approach to get insight into the diagnoses that led to visual impairment and thus to prescription of LVAs to our study population. We first looked at the overall distribution of ophthalmic diagnoses within our study population. Therefore, we selected most certain ophthalmic ICD-10-GM codes (ICD codes H00–H59) from the inpatient and outpatient care, which are diagnoses coded as ‘confirmed’ within the outpatient care and diagnoses coded

as 'discharge diagnosis' within the inpatient care. Next, we calculated the treatment prevalence for the diagnoses that most often occurred within our study population and that are most commonly related to visual impairment. These comprised of diagnoses codes for macular degeneration, glaucoma, diabetic retinopathy and visual impairment.

To minimalize the risk of false-positive diagnoses in the calculation of treatment prevalence, diagnoses need to be validated.[39] Commonly used internal validation strategies in studies with German healthcare claims data are the M2Q and the M1S criterion.[40,41] M2Q stands for a minimum of two quarters and requires a coded diagnosis in at least two quarters within a year. This approach is commonly used to validate outpatient care diagnoses. M1S stands for a minimum of one quarter within the inpatient hospital sector ('stationary' care in Germany) and requires a coded discharge diagnosis in one quarter.

We calculated diagnosis prevalence of macular degeneration, glaucoma, diabetic retinopathy and visual impairment by selecting individuals who had ≥1 discharge diagnosis within the inpatient care and/or ≥2 confirmed diagnoses in a minimum of two of four quarters (1-year period) within the outpatient care. Table 1 shows the diagnoses codes that were used for validation of the different ophthalmic diseases.

For insights into physical comorbidity, we looked at the general distribution of comorbid physical diseases within the study population. We therefore selected certain ICD-10-GM chapters relating to physical comorbidity (Chapter 1-4, 6, 8-14). Having physical comorbidity was defined as having ≥1 registered 'discharge diagnosis' (inpatient care) and/or ≥2 'confirmed' diagnoses (outpatient care) within at least one other of the selected ICD-10-GM chapters in a minimum of two of four quarters (1-year period) per year.

TABLE 1. Selection of ICD-10-GM codes for ophthalmic diagnosis validation

Ophthalmic diagnosis	ICD-10-GM diagnosis codes
Macular degeneration	H35.3
Glaucoma	H40.-, H40.0, H40.1, H40.2, H40.3, H40.4, H40.5, H40.6, H40.8, H40.9, H42.-, H42.0, H42.8
Diabetic retinopathy	H36.0, E10.3, E11.3, E12.3, E13.3, E14.3
Visual impairment	H54.0, H54.1, H54.2, H54.3, H54.4

Mental comorbidity was investigated by looking at the distribution of diagnoses within chapter 5 of the ICD-10-GM (Mental, Behavioral and Neurodevelopmental disorders) and the respective F-diagnoses. For defining mental comorbidity, the same diagnosis validation was applied to the relating F-diagnoses as for physical comorbidity. This also accounts for mental comorbidity at the level of the diagnosis.

Statistical analyses

Descriptive statistics of the study population, as well as their sociodemographic and clinical characteristics were examined. Furthermore, trends in characteristics were investigated by defining the year of observation as independent variable and the different characteristics as dependent variable. For the analysis, most characteristics were dichotomized and a logistic regression was applied. Number of LVAs prescribed and age were defined as continuous dependent variables and were log-transformed due to a non-normal distribution, for these characteristics a linear regression analysis was conducted. The year 2014 was set as the reference and annual changes in the dependent variables in 2015 until 2017 were reported with respect to that year. There were missing values per year for some clinical characteristics, namely for ophthalmic diagnoses and physical and mental comorbidities. As the missing values were <5%, they were not imputed for the analyses.[42] A Bonferroni correction for multiple testing was conducted by dividing the significance level of 0.05 by the number of models (16). Descriptive analyses were conducted with SQL programming language, regression analyses were conducted with the PROC LOGISTIC and the PROC REG procedure in SAS software version 9.4 (SAS Institute Inc., Cary, NC, USA).

RESULTS

LVA prescription

Between 2014 and 2017, 781 (~0.2%) out of ~500,000 unique insured individuals received an LVA prescription. However, 12 individuals died during the study period (Table 2). LVA provision decreased by 19% between 2014 and 2015 (n=217 in 2015 vs. *n*=268 in 2014), increased by 13% between 2015 and 2016 (n=245 in 2016 vs. n=217 in 2015) and decreased again by 3% between 2016 and 2017 (n=238 in 2017 vs. n=245 in 2016). The majority of the study population (*N*=781) received an LVA prescription in only one year (81.0%) with a mean annual number of prescribed LVAs of 1 (SD=0.9). On average, individuals most often obtained a prescription of visual aids (74.1%). A mean of 28.3% received a prescription for aids for blindness. Of all types of LVAs, magnifiers (35.8%), screen readers (34.3%) and canes (17.1%) were most commonly prescribed. Furthermore, individuals mainly received their prescription by an ophthalmologist (75.4%). In an average of 5.3%, the prescription came from the GP and in 7.1% from other medical specialists. Aids for blindness were mainly prescribed to individuals younger than 60 years old compared to individuals aged 60 years and older (15.5% vs. 12.8%, Table 3). However, this was not a large difference. With respect to visual aids the opposite could be observed (64.3% ≥60 years vs. 9.8% <60 years). There were no significant trends with respect to characteristics relating to LVA prescription (Table 4).

Sociodemographic characteristics

The study population was mainly female (68.7%), 60 years or older (75.3%), unemployed (91.5%) and 24.5% was of working-age (15 – <65 years), of which 33.8% was employed. No significant trends were found with respect to these sociodemographic characteristics.

Clinical characteristics

Between 2014 and 2017, an average 97.2% of the study population were treated in outpatient and/or inpatient care and received an ophthalmic condition registered by a medical specialist, 90.3% obtained their diagnosis by an ophthalmologist. Most prevalent ophthalmic ICD-10-GM diagnoses that related to visual impairment were macular degeneration (50.6%) and/or glaucoma (25.9%), 77.2% had other eye diseases which they could have had in addition to the three most prevalent diagnoses. Furthermore, almost the entire study population had physical comorbidity (94.3%) and almost half had mental comorbidity (43.1%). No significant trends were found regarding ophthalmic diagnoses, physical comorbidity and mental comorbidity.

TABLE 2. Characteristics of the study population in 2014-2017 (N=781)

	2014 n=268	2015 n=217	2016 n=245	2017 n=238	Mean (4 years)
	n (%)	n (%)	n (%)	n (%)	N %
LVA prescriptions					
Type of LVAs[a]					
Aids for blindness	71 (26.5)	68 (31.3)	64 (26.1)	71 (29.8)	68.5 (28.3)
Electronic systems for information processing and output	12 (4.5)	8 (3.7)	15 (6.1)	9 (3.8)	11.0 (4.5)
Canes	41 (15.3)	41 (18.9)	33 (13.5)	51 (21.4)	41.5 (17.1)
Other	26 (9.7)	21 (9.7)	25 (10.2)	18 (7.6)	22.5 (9.3)
Visual aids	206 (76.9)	155 (71.4)	187 (76.3)	169 (71.0)	179.3 (74.1)
Magnifiers	89 (33.2)	78 (35.9)	97 (39.6)	83 (34.9)	86.8 (35.8)
Screen readers	100 (37.3)	66 (30.4)	86 (35.1)	80 (33.6)	83.0 (34.3)
Other	28 (10.4)	24 (11.1)	13 (5.3)	10 (4.2)	18.8 (7.7)
Number of prescribed LVAs (N=1281)	361 (28.2)	283 (22.1)	305 (23.8)	332 (25.9)	320.3 (25.0)
Number of prescribed LVAs per person, range 1-15, mean (SD)	1 (0.6)	1 (1.3)	1 (0.8)	1 (0.8)	1 (0.9)
Prescribing medical specialist[b]					
Missing	48 (17.9)	34 (15.7)	38 (15.5)	34 (14.3)	38.5 (15.9)
Ophthalmologist	201 (75.0)	164 (75.6)	187 (76.3)	178 (74.8)	182.5 (75.4)
General pracitioner	9 (3.4)	15 (6.9)	11 (4.5)	16 (6.7)	12.8 (5.3)
Other	18 (6.7)	11 (5.1)	18 (7.3)	22 (9.2)	17.3 (7.1)
Sociodemographic characteristics					
Sex, female	178 (66.4)	150 (69.1)	174 (71.0)	163 (68.5)	166.25 (68.7)
Age, y, range 5-105, mean (SD)	70 (21.7)	67 (22.7)	72 (22.2)	70 (23.3)	69.8

TABLE 2. (continued)

	2014 n=268	2015 n=217	2016 n=245	2017 n=238	Mean (4 years)
	n (%)	n (%)	n (%)	n (%)	N %
Age group					
0-14	7 (2.6)	6 (2.8)	13 (5.3)	12 (5.0)	9.5 (3.9)
15-34	17 (6.3)	19 (8.7)	5 (2.0)	14 (5.9)	13.8 (5.7)
35-49	20 (7.5)	20 (9.2)	12 (4.9)	13 (5.5)	16.3 (6.7)
50-59	24 (9.0)	21 (9.7)	19 (7.8)	17 (7.1)	20.3 (8.4)
60-69	23 (8.6)	19 (8.7)	21 (8.6)	20 (8.4)	20.8 (8.5)
70-79	46 (17.2)	44 (20.3)	46 (18.8)	44 (18.5)	45.0 (18.6)
80+	131 (48.9)	88 (40.5)	129 (52.7)	118 (49.6)	116.5 (48.1)
≥60	200 (74.6)	151 (69.6)	196 (80.0)	182 (76.5)	182.3 (75.3)
<60	68 (25.4)	66 (30.4)	49 (20.0)	56 (23.5)	59.8 (24.7)
Working status					
Working (Age range, y, 23 – 79)	28 (10.4)	24 (11.1)	15 (10.3)	15 (6.3)	9.5 (8.5)
Not working (Age range, y, 5 – 105)	240 (89.6)	193 (88.9)	230 (93.9)	223 (93.7)	221.5 (91.5)
Working-age (Age range, y, 15 – <65)	69 (25.7)	67 (30.9)	49 (20.0)	52 (21.8)	59.3 (24.5)
Working	27 (39.1)	24 (35.8)	15 (30.6)	14 (26.9)	20.0 (33.8)
Not working	42 (60.9)	43 (64.2)	34 (69.4)	38 (73.1)	39.3 (66.2)
Clinical characteristics					
Ophthalmic diagnoses[c]	264 (98.5)	209 (96.3)	233 (95.1)	235 (98.7)	235.3 (97.2)
Missing	4 (1.5)	8 (3.7)	12 (4.9)	3 (1.3)	6.8 (2.8)
Macular degeneration	139 (51.9)	99 (45.6)	129 (52.7)	123 (51.7)	122.5 (50.6)
Glaucoma	76 (28.4)	56 (25.8)	60 (24.5)	59 (24.8)	62.8 (25.9)
Diabetic retinopathy	31 (11.6)	14 (6.5)	20 (8.2)	8 (3.4)	18.3 (7.5)
VI	67 (25.0)	60 (27.6)	64 (26.1)	60 (25.2)	62.8 (25.9)
Other	213 (79.5)	175 (80.5)	189 (77.1)	170 (71.4)	186.8 (77.2)
Diagnosis by Ophthalmologist[d]	245 (91.4)	192 (91.9)	218 (93.6)	219 (93.2)	218.5 (90.3)

TABLE 2. (continued)

	2014 n=268	2015 n=217	2016 n=245	2017 n=238	Mean (4 years)
	n (%)	n (%)	n (%)	n (%)	N %
Physical comorbidity	253 (94.4)	204 (94.0)	229 (93.47)	227 (95.4)	228.3 (94.3)
Mental comorbidity	121 (45.1)	89 (41.0)	107 (43.7)	100 (42.0)	104.3 (43.1)
Mood (affective) disorders[e]	56 (46.3)	45 (50.6)	56 (52.3)	53 (53.0)	52.5 (50.4)
Anxiety, dissociative, stress- related, somatoform and other nonpsychotic mental disorders[e]	49 (40.5)	35 (39.3)	40 (37.4)	37 (37.0)	40.25 (38.6)
Mental disorders due to known physiological conditions[e]	29 (24.0)	13 (14.6)	21 (19.6)	19 (19.0)	20.5 (19.7)
Other[e]	30 (24.8)	29 (32.6)	39 (36.4)	27 (27.0)	31.3 (30.0)

Data are n/n (%) or n/N (%), unless otherwise specified. Abbreviations: LVAs, low vision aids. VI, visual impairment. SD, standard deviation.
[a]Individuals could have had a prescription for more than one type of low vision aid per year and could have a prescription in more than one year.
[b]The number of prescribing medical specialists relative to the number of individuals. Individuals could have received both visual aids and aids for blindness, and these low vision aids could have been prescribed by different healthcare providers.
[c]Number of individuals that received a 'confirmed' ophthalmic diagnosis within the outpatient care or a 'discharge diagnosis' within the inpatient care. Each diagnosis is dichotomous (yes/no). Individuals could have been treated for more than one ophthalmic condition per year.
[d]Number of individuals that received their ophthalmic diagnosis by an ophthalmologist.
[e]Data are n/121 (%), n/89 (%), n/107 (%), n/100 (%) for the years 2014-2017 for individuals who received an LVA prescription and a mental comorbidity. Each diagnosis is dichotomous (yes/no). Individuals could have been treated for multiple mental disorders.

TABLE 3. Distribution of type of low vision aids prescribed by age and by sex in 2014-2017 (N=781)

	2014 n=268		2015 n=217		2016 n=245		2017 n=238		Mean (4 years)
	n	%	n	%	n	%	n	%	
Age									
Aids for blindness[a]									
<60	41	15.3	38	17.5	28	11.4	43	18.1	37.5 (15.5)
≥60	30	12.6	30	13.8	36	14.7	28	11.8	31.0 (12.8)
Visual aids[a]									
<60	28	10.4	32	14.7	22	9.0	13	5.5	23.8 (9.8)
≥60	178	66.4	123	56.7	165	67.3	156	65.5	155.5 (64.3)
Sex									
Aids for blindness[a]									
Female	44	16.4	45	20.7	36	14.7	36	15.1	40.3 (16.6)
Male	27	10.1	23	10.6	28	11.4	35	14.7	28.3 (11.7)
Visual aids[a]									
Female	140	52.2	109	50.2	142	58.0	129	54.2	130.0 (53.7)
Male	66	24.6	46	21.2	45	18.4	40	16.8	49.3 (20.3)

[a]Patients could have had a prescription for both, aids for blindness and visual aids per year.

TABLE 4. Results of logistic and linear regression analysis: Effects of time (year) of characteristics of the study population (N=781)

	2015[a]		2016[a]		2017[a]	
Outcome variables	OR [95%]	p*	OR [95%]	p*	OR [95%]	p*
LVA provision						
Type of LVAs						
Aids for blindness[b]	1.27 [0.85–1.88]	0.26	0.98 [0.66–1.45]	0.80	1.18 [0.90–1.74]	0.57
Visual aids[b]	0.75 [0.50–1.13]	0.32	0.97 [0.65–1.46]	0.33	0.74 [0.50–1.10]	0.23
Number of prescribed LVAs per person†	-0.03 [-0.10–0.04]	0.44	-0.05 [-0.12–0.01]	0.12	-0.01 [-0.09–0.05]	0.60
Prescribing medical specialist						
Ophthalmologist[c]	1.03 [0.68–1.56]	0.95	1.08 [0.72–1.61]	0.71	0.99 [0.66–1.48]	0.79
General practitioner[c]	2.14 [0.92–4.98]	0.19	1.35 [0.55–3.32]	0.58	2.07 [0.90–4.79]	0.23
Other[c]	0.74 [0.34–1.60]	0.19	1.10 [0.56–2.17]	0.78	1.42 [0.74–2.71]	0.13
Sociodemographic characteristics						
Sex (Female)	1.13 [0.77–1.66]	0.90	1.24 [0.85–1.80]	0.32	1.10 [0.78–1.60]	0.91
Age†	-0.05 [-0.14–0.05]	0.33	0.01 [-0.08–0.11]	0.78	-0.01 [-0.11–0.08]	0.76
Working (not working)	1.07 [0.60–1.90]	0.08	0.56 [0.29–1.07]	0.16	0.58 [0.30–1.11]	0.20
Clinical characteristics						
Ophthalmic diagnosis						
Macular degeneration[d]	0.78 [0.54–1.12]	0.10	1.03 [0.73–1.46]	0.42	1.99 [0.70–1.41]	0.66
Glaucoma[d]	0.88 [0.59–1.32]	0.99	0.82 [0.55–1.22]	0.58	0.83 [0.56–1.24]	0.67
Diabetic retinopathy[d]	0.53 [0.27–1.02]	0.83	0.68 [0.38–1.23]	0.35	0.27 [0.20–0.59]	0.01
Visual impairment[d]	1.15 [0.76–1.72]	0.51	1.06 [0.71–1.58]	0.95	1.01 [0.68–1.51]	0.75
Other[d]	1.08 [0.68–1.69]	0.17	0.87 [0.57–1.33]	0.92	0.65 [0.43–0.97]	0.01
Physical comorbidity[d]	0.93 [0.43–2.00]	0.80	0.85 [0.41–1.76]	0.50	1.22 [0.55–2.72]	0.42
Mental comorbidity[d]	0.85 [0.59–1.21]	0.50	0.94 [0.67–1.34]	0.79	0.88 [0.62–1.25]	0.73

Reference group: [a]2015; [b]no prescription for this type of low vision aid; [c]no prescription by this type of medical specialist, [d]no diagnosis for this type of diagnosis*Reported p-values are corrected. Bold is significant at p<0.003 (i.e. after Bonferroni correction).
†regression coefficients are obtained from the linear regression analysis.

DISCUSSION

This retrospective study aimed to investigate LVA provision in an urban setting in Germany. Visual aids were the most often prescribed type of LVAs and next to ophthalmologists, GPs and other medical specialists seemed to have played a role in LVA provision as well. Although we found some annual fluctuations in characteristics of individuals with an LVA prescription, no significant trends were found.

Our study showed that 781 individuals received an LVA prescription between 2014 and 2017 of a population of approximately 500.000 with an SHI at one of four large insurers in Cologne. In Germany, the estimated prevalence of having a visual impairment in the general population is between 0.6 and 1.2%.[9,10,43] For Cologne, this means that approximately 6,500 to 13,000 persons have a visual impairment based on 1,084,000 inhabitants. Extrapolating the number of LVAs that was prescribed to the overall population of Cologne yields an estimated 1,562 individuals with an LVA prescription in the four-year period (or N=390 LVAs per year). Considering the estimated number of persons with visual impairment in Cologne, the number of LVAs that were actually prescribed seems rather low. One possible explanation can be that prescriptions occur at longer time intervals than could be covered by the data used. Another explanation could be that patients paid for the LVAs themselves or already had an LVA before 2014-2017. However, it might also indicate there is a need for information provision about funding of LVAs by health insurance companies or healthcare providers. Future studies should further investigate LVA provision by starting off with a sample of people with a visual impairment, as this information was not available in our data. Furthermore, there were annual fluctuations with respect to the number of people that received an LVA prescription, but no stable trend could be observed.

Of the investigated LVAs, visual aids were most often prescribed and in accordance with previous studies, screen readers and magnifiers were the most frequently prescribed types of visual aids, which indicates a magnification requirement of individuals with an LVA prescription of ≥1.5-fold for magnifiers and ≥6-fold for screen readers, respectively.[36-38,44-46]

Moreover, there were differences in provision between aids for blindness and visual aids with respect to age. Where the former where mostly prescribed to individuals younger than 60, visual aids were mostly prescribed to individuals aged 60 and older. An explanation could be that in older individuals, the eye disease resulting in visual impairment might be more progressed and consequently, aids for blindness may be prescribed more frequently. As we had no insight into severity of the visual impairment, more research is needed to examine the provision of type of LVAs by severity of the visual impairment.

Individuals who received an LVA prescription were mainly female, 60 years and older and had macular degeneration and/or glaucoma. These sociodemographic characteristics can be explained by the epidemiology of visual impairment in Germany.[7] Besides that, of the individuals who received an LVA and were of working-age, only 34% were employed. This is similar to employment rates of people with visual impairment in other high-income

countries and is lower compared to the employment rate of 77% in the general working-age population in Germany, indicating reduced work participation of people with visual impairment, as found in other studies.[47-50]

Our results further revealed that the study population had a high prevalence of physical comorbidity (94%) and mental comorbidity (43%). This might partly be explained by the definitions we used to investigate comorbidities, which might have caused an overestimation. However, studies have shown that both mental and physical comorbidity in people with a visual impairment are common, which our results seem to confirm.[4,51] Furthermore, our study population was mainly 60 years or older (75%). As the prevalence of physical comorbidities increases with age, older adults often have multiple physical comorbidities, which explains our high numbers as well.[52]

Moreover, results indicate that, next to ophthalmologists, GPs and other medical specialists play a role in LVA provision as well. Although in the majority of the study population, LVAs were provided by ophthalmologists, some individuals received their prescription for both visual aids and aids for blindness by a GP or other medical specialists. This is finding is plausible for aids for blindness, but not for visual aids, as for the latter the guideline for medical aids requires a prescription by an ophthalmologist. This discrepancy might be attributed to coding errors in the claims data, or instances were medical specialists deviated from the guideline. For example in patients for whom visiting their GP or other medical specialist is easier, e.g., due to impaired mobility, compared to visiting their ophthalmologist.

Strengths and limitations

To the best of our knowledge, this is the first study examining LVA provision in an urban setting in Germany based on population-based healthcare claims data. A strength of our study is that we were able to examine LVA provision over a four-year period using a population-based sample that included people insured at four large insurers, thereby enhancing representativeness of the findings.

However, by only including SHI and not PHI insurers and only four of the 113 to 123 SHI insurers in 2014-2017, our results may have been affected by selection bias and therefore reduced representativeness. For example, research has found differences regarding education level and socioeconomic status between different SHI insurers.[53]

Besides that, this study only represents reimbursable LVA provision. LVAs that are not funded by health insurers were not included.

As insurance claims data were not designed for research, but for billing purposes, potential coding errors and invalidity are well known challenges in research based on this type of data.[39] This might have affected our results. To reduce possible bias, we performed plausibility checks and validated diagnoses internally. However, the ophthalmic diagnoses we investigated in our study have not been validated on German claims data by other

studies and we therefore had no reference. More research on this topic is warranted to assess the validity of our results.

Moreover, as in claims data no information is available on visual acuity, visual field defects and severity of the visual impairment, we could not examine these parameters in our analyses.

Lastly, this study reflects the LVA provision context of Cologne, a large city in the west of Germany. As there are great differences regarding healthcare provision between rural and urban areas, results should cautiously be applied to other German healthcare contexts. This also accounts for translation of the study results to other countries, as LVA prescription guidelines and healthcare funding regulations differ largely internationally.

Conclusion

Between 2014 and 2017, 781 individuals received an LVA prescription. They had characteristics which mostly can be explained by the epidemiology of visual impairment. Results indicate that individuals that received LVAs have a magnification requirement of ≥1.5-fold and ≥6-fold. Furthermore, results indicate that besides ophthalmologists, GPs and other medical specialists seem to play a role in LVA provision as well, which should be taken into account by policy makers when planning interventions for increasing LVS provision. Our findings provide a starting point to examine LVS provision in Germany. Future studies should investigate LVA provision among people with a visual impairment in Germany in different urban and rural settings, and examine differences between those who get an LVA prescription and redeem it and those who do not. This way insights into possible differences and inequalities may become clear. Finally, it would be valuable to include other types of LVS, such as psychological therapy or support and training in activities of daily living, as well as additional forms of funding to get a more comprehensive understanding of LVS provision in Germany and its adequacy.

REFERENCES

1. Bourne R, Steinmetz JD, Flaxman S, Briant PS, Taylor HR, Resnikoff S, et al. Trends in prevalence of blindness and distance and near vision impairment over 30 years: an analysis for the Global Burden of Disease Study. *Lancet Glob Health.* 2021;9(2):e130-e43.
2. de Boer MR, Pluijm SM, Lips P, Moll AC, Volker-Dieben HJ, Deeg DJ, et al. Different aspects of visual impairment as risk factors for falls and fractures in older men and women. *J Bone Miner Res.* 2004;19(9):1539-47.
3. Kempen GI, Ballemans J, Ranchor AV, van Rens GH, Zijlstra GA. 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. *Qual Life Res.* 2012;21(8):1405-11.
4. van der Aa HP, Hoeben M, Rainey L, van Rens GH, Vreeken HL, van Nispen RM. Why visually impaired older adults often do not receive mental health services: the patient's perspective. *Qual Life Res.* 2015;24(4):969-78.
5. van Nispen RM, Vreeken HL, Comijs HC, Deeg DJ, van Rens GH. Role of vision loss, functional limitations and the supporting network in depression in a general population. *Acta Ophthalmol.* 2016;94(1):76-82.
6. Köberlein J, Beifus K, Schaffert C, Finger RP. The economic burden of visual impairment and blindness: a systematic review. *BMJ open.* 2013;3(11):e003471.
7. Finger RP, Fimmers R, Holz FG, Scholl HPN. Prevalence and causes of registered blindness in the largest federal state of Germany. *Br J Ophthalmol.* 2011;95(8):1061-7.
8. Federal Statistical Office. Current population of Germany 2024 [cited 2024 Apr 11]. Available from: https://www.destatis.de/EN/Themes/Society-Environment/Population/Current-Population/_node.html.
9. Finger RP, Bertram B, Wolfram C, Holz FG. Blindness and visual impairment in Germany: a slight fall in prevalence. *Dtsch Arztebl Int.* 2012;109(27-28):484-9.
10. Bertram B. Blindheit und Sehbehinderung in Deutschland: Ursachen und Häufigkeit [Blindness and visual impairment in Germany: Causes and prevalence]. *Der Augenarzt.* 2005;39(6):267-8.
11. Knauer C, Pfeiffer N. Erblindung in Deutschland – heute und 2030 [Blindness in Germany - today and 2030]. *Der Ophthalmologe.* 2006;103(9):735-41.
12. van Nispen RMA, Virgili G, Hoeben M, Langelaan M, Klevering J, Keunen JEE, et al. Low vision rehabilitation for better quality of life in visually impaired adults. *Cochrane Database Syst Rev.* 2020(1).
13. Pfau N, Kern AO, Wolfram C, Kalcklösch M, Prütz F. Blindheit und Sehbehinderung [Blindness and visual impairment]2017. Available from: https://doi.org/10.17886/rki-gbe-2017-002.
14. Maritzen A, Kamps N. Rehabilitation bei Sehbehinderung und Blindheit [Rehabilitation for visual impairment and blindness]: Springer-Verlag; 2013.
15. Heil C. Psychotherapeutische Arbeit mit Menschen mit Körper-und Sinnesbehinderungen [Psychotherapy for people with physical and sensory disabilities]. Psychotherapeutenjournal [Internet]. 2017; 16(1):[11-8 pp.]. Available from: https://www.psychotherapie-heil.de/resources/PTJ_1_2017_Heil.pdf.
16. Deutscher Blinden- und Sehbehindertenverband e.V. Beratung & Reha [Counseling & Rehabilitation] 2022 [cited 2022 Mar 13]. Available from: https://www.dbsv.org/beratung-reha.html.
17. Grein HJ. [Low vision: provision of the visually handicapped with magnifying aids. II. Matching and prescription]. *Ophthalmologe.* 2002;99(11):884-900.

18. Blickpunkt Auge. Ratgeber Recht für blinde und sehbehinderte Menschen [Legal guide for blind and visually impaired people] 2021 [cited 2022 Mar 13]. Available from: https://www.dbsv.org/files/ueber-dbsv/publikationen/broschueren/Ratgeber_Recht_barrierefrei.pdf.
19. Lam N, Leat SJ. Reprint of: Barriers to accessing low-vision care: the patient's perspective. *Can J Ophthalmol.* 2015;50 Suppl 1:S34-9.
20. Matti AI, Pesudovs K, Daly A, Brown M, Chen CS. Access to low-vision rehabilitation services: barriers and enablers. *Clin Exp Optom.* 2011;94(2):181-6.
21. Kaleem MA, West SK, Im L, Swenor BK. Referral to Low Vision Services for Glaucoma Patients: Referral Criteria and Barriers. *J Glaucoma.* 2018;27(7):653-5.
22. Goldstein JE, Guo X, Boland MV, Swenor BK. Low Vision Care - Out of Site. Out of Mind. *Ophthalmic Epidemiol.* 2020:1-7.
23. O'Connor PM, Mu LC, Keeffe JE. Access and utilization of a new low-vision rehabilitation service. *Clin Exp Optom.* 2008;36(6):547-52.
24. Kaldenberg J. Low vision rehabilitation services: Perceived barriers and facilitators to access for older adults with visual impairment. *Br J Occup Ther.* 2019;82(8):466-74.
25. Cuypers M, Tobi H, Huijsmans CAA, van Gerwen L, Ten Hove M, van Weel C, et al. Disparities in cancer-related healthcare among people with intellectual disabilities: A population-based cohort study with health insurance claims data. *Cancer medicine.* 2020;9(18):6888-95.
26. Stelzer D, Graf E, Köster I, Ihle P, Günster C, Dröge P, et al. Assessing the effect of a regional integrated care model over ten years using quality indicators based on claims data – the basic statistical methodology of the INTEGRAL project. *BMC Health Serv Res.* 2022;22(1):247.
27. Basilious A, Basilious A, Mao A, Hutnik CML. Trends in low vision care provided by ophthalmologists in Ontario between 2009 and 2015. *Can J Ophthalmol.* 2019;54(2):229-36.
28. Stolwijk ML, Van Nispen RMA, van Rens GHMB. Characteristics and healthcare utilization among patients of low vision services: a retrospective population-based descriptive study with healthcare claims. *Invest Ophthalmol Vis Sci.* 2021;62(8):3597-.
29. Hoffmann W, Latza U, Baumeister SE, Brünger M, Buttmann-Schweiger N, Hardt J, et al. Guidelines and recommendations for ensuring Good Epidemiological Practice (GEP): a guideline developed by the German Society for Epidemiology. *Eur J Epidemiol.* 2019;34(3):301-17.
30. Working Group for the Collection and Use of Secondary Data (AGENS) of the German Society for Social Medicine and Prevention (DGSMP) and the German Society for Epidemiology (DGEpi). Good Practice in Secondary Data Analysis (GPS) 2014 [cited 2023 Jan 20]. Available from: https://www.dgepi.de/assets/Leitlinien-und-Empfehlungen/GPS_revision2-final_august2014.pdf.
31. Busse R, Blümel M, Knieps F, Bärnighausen T. Statutory health insurance in Germany: a health system shaped by 135 years of solidarity, self-governance, and competition. *Lancet.* 2017;390(10097):882-97.
32. European Observatory on Health Systems and Policies, Blümel M, Spranger A, Achstetter K, Maresso A, Busse R. Germany: health system review. Copenhagen: World Health Organization. Regional Office for Europe; 2020 [cited 2022 Mar 13]. Available from: https://apps.who.int/iris/handle/10665/341674.
33. Scholten N, Ihle P, Pfaff H, für das CoRe-Net K, Albus C, Jessen J, et al. Nachhaltige Infrastruktur für die Versorgungsforschung: Der Aufbau einer regionalen, krankenkassenübergreifenden GKV-Routinedatenbank. *Gesundheitswesen.* 2021;83(06):463-9.

34. Spitzenverband G. Hilfsmittelverzeichnis [Medical aids list] 2022 [Available from: https://hilfsmittel.gkv-spitzenverband.de/home/verzeichnis/3bed4717-5674-42cc-b5c7-7c4fa66a2f94%2F11c0894c-1178-4b74-9a1a-ecd2d8e6e6a2.
35. Bundesausschuss G. Hilfsmittel-Richtlinie über die Verordnung von Hilfsmitteln in der vertragsärztlichen Versorgung (Hilfsmittel-Richtlinie/HilfsM-RL) in der Neufassung vom 01.04.2021 [Guideline on the Prescription of Aids in Ambulatory Medical Care in the Revised Version of 01.04.2021] 2022 [cited 2024 Apr 25]. Available from: https://www.g-ba.de/downloads/62-492-1666/HilfsM-RL_2018-07-19_iK-2018-10-03.pdf.
36. Bundesausschuss G. Hilfsmittel-Richtlinie über die Verordnung von Hilfsmitteln in der vertragsärztlichen Versorgung (Hilfsmittel-Richtlinie/HilfsM-RL) in der Neufassung vom 29.10.2014 [Guideline on the Prescription of Aids in Ambulatory Medical Care in the Revised Version of 29.10.2014] 2014 [cited 2022 Mar 25]. Available from: https://www.g-ba.de/downloads/62-492-934/HilfsM-RL_2014-07-17.pdf.
37. Bundesausschuss G. Hilfsmittel-Richtlinie über die Verordnung von Hilfsmitteln in der vertragsärztlichen Versorgung (Hilfsmittel-Richtlinie/HilfsM-RL) in der Neufassung vom 24.03.2016 [Guideline on the Prescription of Aids in Ambulatory Medical Care in the Revised Version of 24.03.2016] 2016 [cited 2022 Mar 25]. Available from: https://www.g-ba.de/downloads/62-492-1143/HilfsM-RL_2015-12-17_iK-2016-03-24.pdf.
38. Bundesausschuss G. Hilfsmittel-Richtlinie über die Verordnung von Hilfsmitteln in der vertragsärztlichen Versorgung (Hilfsmittel-Richtlinie/HilfsM-RL) in der Neufassung vom 17.02.2017[Guideline on the Prescription of Aids in Ambulatory Medical Care in the Revised Version of 17.02.2017] 2017 [cited 2022 Mar 25]. Available from: https://www.g-ba.de/downloads/62-492-1352/HilfsM-RL_2016-11-24_iK-2017-02-17.pdf.
39. Swart E. Health Care Utilization Research using Secondary Data. In: Janssen C, Swart E, von Lengerke T, editors. Health Care Utilization in Germany: Theory, Methodology, and Results. New York, NY: Springer New York; 2014. p. 63-86.
40. Köster I, Mehl C, Siegel A, Graf E, Stelzer D, Farin-Glattacker E, et al. [Correction: Operationalization of Quality Indicators with Routine Data Using the Example of the Evaluation of "Integrated Care Healthy Kinzigtal"]. *Gesundheitswesen.* 2021;83(S 02):e58.
41. Köster I, Mehl C, Siegel A, Graf E, Stelzer D, Farin-Glattacker E, et al. [Operationalization of Quality Indicators with Routine Data Using the Example of the Evaluation of "Integrated Care Healthy Kinzigtal"]. *Gesundheitswesen.* 2021;83(S 02):S87-s96.
42. Little RJ, Rubin DB. Statistical analysis with missing data: John Wiley & Sons; 2019.
43. Federal Statistical Office. Statistik der schwerbehinderten Menschen 2019 [cited 2022 Mar 13]. Available from: https://www.destatis.de/DE/Themen/Gesellschaft-Umwelt/Gesundheit/Behinderte-Menschen/_inhalt.html.
44. Altpeter EK, Nguyen NX. [Requirements for low vision magnification aids in age-related macular degeneration: Data from the Tübingen low vision clinic (comparison of 2007-2011 with 1999-2005)]. *Ophthalmologe.* 2015;112(11):923-8.
45. Nguyen NX, Weismann M, Trauzettel-Klosinski S. [Spectrum of ophthalmologic and social rehabilitation at the Tübinger Low-Vision Clinic : a retrospective analysis for 1999-2005]. *Ophthalmologe.* 2008;105(6):563-9.
46. Violan C, Foguet-Boreu Q, Flores-Mateo G, Salisbury C, Blom J, Freitag M, et al. Prevalence, Determinants and Patterns of Multimorbidity in Primary Care: A Systematic Review of Observational Studies. *PLOS ONE.* 2014;9(7):e102149.
47. Goertz YHH, Houkes I, Nijhuis FJN, Bosma H. Factors associated with participation on the competitive labour market of people with visual impairments in The Netherlands. *Work.* 2017;58(3):251-61.

48. Knapen J, Grosscurt R, van Schelven F, Boeije H, Bastiani H, Helleman S. Het werkt anders. *Handreiking om de arbeidsparticipatie van mensen met een visuele of auditieve beperking te bevorderen Utrecht: Nivel.* 2020.
49. Brunes A, Heir T. Visual impairment and employment in Norway. *BMC Public Health.* 2022;22(1):648.
50. Federal Statistical Office. Employment 2024 [cited 2024 Apr 26]. Available from: https://www.destatis.de/EN/Themes/Labour/Labour-Market/Employment/_node.html.
51. Stolwijk ML, van Nispen RMA, van der Pas SL, van Rens G. A retrospective big data study using healthcare insurance claims to investigate the role of comorbidities in receiving low vision services. *Front Health Serv.* 2024;4:1264838.
52. Marengoni A, Angleman S, Melis R, Mangialasche F, Karp A, Garmen A, et al. Aging with multimorbidity: A systematic review of the literature. *Ageing Res Rev.* 2011;10(4):430-9.
53. Hoffmann F, Koller D. [Different Regions, Differently Insured Populations? Socio-demographic and Health-related Differences Between Insurance Funds]. *Gesundheitswesen.* 2017;79(1):e1-e9.

CHAPTER 7

Summary and general discussion

Irreversible loss of sight can have a huge impact on an individuals' life, affecting, among others, activities of daily living, mental wellbeing, independence, work participation and consequently, quality of life. Low vision services (LVS) can help people with severe visual impairment to improve or gain back their quality of life through different interventions aimed at enhancing independence and teaching them to adapt to or compensate for their vision loss. Despite the benefits of LVS, not everyone potentially in need of LVS receives that care and barriers in the referral pathways to LVS have been reported internationally. However, a comprehensive understanding of factors influencing the referral pathways to LVS is missing, especially from high-income countries.

In view of this, this thesis focused on referral to LVS. The main aim was to identify factors influencing the referral pathways to LVS in high-income countries, by taking the Social Ecological Model into account. To achieve that aim, five studies were conducted. With the first study (*Chapter 2*) the patients' and healthcare professionals' perspective on barriers and facilitators in multidisciplinary LVS access were investigated. The second study focused on trends in multidisciplinary LVS utilization (*Chapter 3*). The third study (*Chapter 4*) was designed to determine predictors of receiving multidisciplinary LVS, after which we further investigated the role of comorbidities in multidisciplinary LVS access (*Chapter 5*). Whereas the first four studies were conducted in the high-income country the Netherlands, the last study aimed to investigate trends in LVS utilization in terms of LVAs in the high-income country Germany (*Chapter 6*).

MAIN FINDINGS

Barriers and facilitators from the perspective of healthcare professionals and visually impaired adults.

Only a few studies elucidated factors influencing the referral pathways of patients to LVS from both the patients' and professionals' perspective. Furthermore, the perspective from high-income countries was missing. Therefore, in ***Chapter 2***, 14 patients, aged 50 years or older with macular degeneration, glaucoma and/or diabetic retinopathy and 16 professionals, including ophthalmologists, low vision optometrists and professionals from a multidisciplinary LVS organization were interviewed to investigate barriers and facilitators in multidisciplinary LVS delivery in the high-income country the Netherlands. These interviews revealed various factors on individual, interpersonal, organizational, community and public policy levels of the Social Ecological Model.

Patients' intrinsic motivation seems to be an important facilitator as well as a barrier in the referral to multidisciplinary LVS. In line with shared-decision making, professionals mentioned to only refer patients that want to be referred and patients eligible for multidisciplinary LVS seem to regularly refuse referral. Furthermore, patients' motivation seems to be influenced by individual patient factors such as perceived impact of the VI, (lack of) acceptance of the VI, disease duration, lack of knowledge or awareness about multidisciplinary LVS, participation needs and attitudes. Additionally, (not) possessing self-advocacy skills as a patient was identified as an important facilitator and barrier.

Furthermore, information provision about multidisciplinary LVS and communication skills of professionals came forward as important barriers and facilitators as well. Whereas half of the interviewed patients stated that they initiated their referral or that they have not been informed by their provider about multidisciplinary LVS, almost all professionals with the authorization to refer (low vison optometrists and ophthalmologists) said to regularly inform patients. Furthermore, some patients reported to have been informed late about multidisciplinary LVS. However, patients did not feel that they have been referred late in due course, as most of them contacted multidisciplinary LVS or initiated referral by themselves. Furthermore, interviews with patients and professionals revealed that communication skills of professionals, such as sensing and timing the right moment to talk about multidisciplinary LVS and to refer patients, actively asking patients questions about daily life functioning, using clear examples, motivating patients, managing expectations, and repeating information may facilitate referral.

Having social support networks was identified as another relevant facilitator from both perspectives. Social support during ophthalmic encounters may facilitate patients' needs identification of multidisciplinary LVS. Patients might be informed by their social network about multidisciplinary LVS and/or the patients' social network may help patients to contact multidisciplinary LVS. Not having a strong social support network might function as a barrier according to interviewed professionals.

Other factors that came forward as facilitators were a longer patient-provider relationship, communication between providers, low vision optometric services, education of healthcare professionals, the Dutch healthcare system, and regional service provision. A short patient-provider relationship, lack of care coordination, time constraints in the ophthalmic practice, fear of stigma of patients, distance to multidisciplinary LVS/lack of transportation of patients, the Dutch healthcare system and long multidisciplinary LVS waiting lists were other barriers that were identified in this study.

Trends in multidisciplinary LVS utilization

In the Netherlands, a downward trend in multidisciplinary LVS uptake has been observed in the past few years since 2015, that is, from the moment multidisciplinary LVS was reimbursed by health insurance as opposed to the Exceptional Medical Expenses Act (AWBZ). In ***Chapter 3***, national trends between 2015 and 2018 in multidisciplinary LVS utilization in the Netherlands were described based on healthcare claims of insurers (Vektis C.V.) to identify parameters that are associated with this downward trend. Specifically, we examined trends in sociodemographic, clinical and contextual characteristics, as well as general healthcare utilization of adult patients (18+) of three multidisciplinary Dutch LVS organizations. The Vektis C.V. dataset included healthcare claims data of the years 2015 to 2018 and of almost all Dutch citizens (17.5 million) (99%) (***Chapter 3-5***).

Our findings revealed that multidisciplinary LVS utilization decreased by 15% between 2015 and 2018. We found that a possible explanation for the decrease in Dutch patients using multidisciplinary LVS might be a decreased distribution of patients treated with intravitreal injections and patients with lens-related diseases within the services. In line with our results, an increase of intravitreal injections in the Netherlands and an increase of cataract surgeries in Europe, including the Netherlands, has been observed. This might indicate that there are more patients that benefit from receiving these treatments, i.e. they might have fewer multidisciplinary LVS needs due to the positive treatment effect.

Moreover, we found that patients who received multidisciplinary LVS were mainly patients of 65 years or older, female, and had macular related eye diseases. Furthermore, multidisciplinary LVS patients mostly had a low or middle high SES and lived in urban areas within 20 km of a multidisciplinary LVS center. Patients who received multidisciplinary LVS received relatively much medical specialist care for physical comorbidity and mental healthcare and multidisciplinary LVS patients were more likely to have physical comorbidity over the years. As demographic forecasts for the Netherlands indicate that the proportion of people aged 65 years or older will increase by 2035, particularly in rural areas, due to demographic ageing and population shifts of younger people to urban areas, a potential point of concern drawn from this study is the possibility of disparities in multidisciplinary LVS access as most people in the Netherlands now live in urban areas.

Predictors of, and the role of comorbidities in receiving multidisciplinary LVS

To get further insight into barriers and facilitators in the referral pathways to LVS in high-income countries, we conducted a study on predictors of receiving multidisciplinary LVS in the Netherlands based on healthcare claims data (***Chapter 4***). We looked at patients' sociodemographic, clinical, contextual characteristics, and their general healthcare utilization as potential predictors.

Patient characteristics that predicted receipt of multidisciplinary LVS were prescriptions for LVAs, ocular-comorbidity, mental comorbidity, receiving occupational therapy, having a hearing disorder, treatment in multiple treatment settings, not living in the west of the Netherlands (urban area), receiving optical coherence tomography scans more often and contact with a GP. Most important explanations that could be drawn from these study results were that healthcare professionals, such as GPs, low vision optometrists and ophthalmologists may already focus on patients' (vision) disability, which might in turn enhance referral and thus receiving multidisciplinary LVS.

Older age, low socioeconomic status (SES), physical comorbidity, treatment in a specialized ophthalmic center, treatment with intravitreal injections, cataract surgery, higher costs for ophthalmic encounters and greater distance to a multidisciplinary LVS center was associated with a lower odds of receiving multidisciplinary LVS. Most important implications from these findings were that special attention should be given to patients of older age, who have a low SES, and who live further away from a multidisciplinary LVS center.

Another interesting finding was that 39% of patients that utilized multidisciplinary LVS in 2018 did not utilize ophthalmic medical specialist care in 2015-2017. This suggests that the group of patients that has not seen their ophthalmologist in the years before, found their way to multidisciplinary LVS anyways.

In ***Chapter 5***, we further examined the association between mental comorbidity and physical comorbidity and receiving multidisciplinary LVS, respectively. We conducted this study against the background that findings from earlier research were contradicting with respect to the role of comorbidities in receiving multidisciplinary LVS, i.e. physical and mental comorbidity were both identified as barriers as well as facilitators. Five models were tested with and without the assumed confounders age, sex, SES, area of residence, amount of ophthalmic diagnoses and the two comorbidity variables, respectively. The model, which included all assumed confounders was found to best describe the association between mental and physical comorbidity and receiving multidisciplinary LVS. According to this model, patients with mental comorbidity had a 1.29 higher odds of receiving multidisciplinary LVS compared to patients with no mental comorbidity after adjustment for assumed confounders. Furthermore, patients with physical comorbidity had a 0.84 lower odds of receiving multidisciplinary LVS compared to those without physical comorbidity.

Our findings indicated that having mental comorbidity facilitates receiving multidisciplinary LVS. The opposite seemed to hold true for physical comorbidity. However, as patients with VI are more susceptible to physical comorbidity by definition and the majority of the study population had physical comorbidity (83%), we concluded that this finding might be less meaningful in terms of policy implications.

LVS provision in Germany

In ***Chapter 6***, we examined the provision of LVS in Germany in an urban setting in Cologne, to explore LVS provision in another high-income country. We specifically looked at low vision aids (LVAs) provision, as these are the only type of LVS which are (partially) funded by health insurance and provided within the context of LVS in Germany. Based on claims data of four large statutory health insurers of Cologne, we investigated sociodemographic and clinical characteristics of individuals who redeemed a prescription for LVAs, as well as trends in their characteristics over a four-year period. The aim was to get insight into which persons utilize LVAs, which LVAs are utilized, and how often they are utilized.

Our results showed that between 2014-2017, 781 (~0.2%) unique individuals out of 500,000 inhabitants of Cologne (~1 million), redeemed an LVA prescription. Individuals who redeemed LVAs were mainly female, 60 years or older, unoccupied and had macular degeneration and/or glaucoma, which can be explained by the epidemiology of visual impairment. Magnifiers and screen readers were most often redeemed by individuals, which indicated a magnification requirement of ≥1.5-fold and ≥6-fold, respectively. Although we did not find any significant trends in characteristics of individuals who redeemed LVAs, the number of LVAs that were prescribed seemed rather low, considering the estimated number of persons with visual impairment in Cologne and extrapolating the number of prescribed LVAs to the overall population (~1,562 individuals with an LVA prescription in the four-year period or N=~390 LVAs per year).

Figure 1 provides an overview of the identified barriers and facilitators from this thesis, categorized into the levels of the Social Ecological Model.[1]

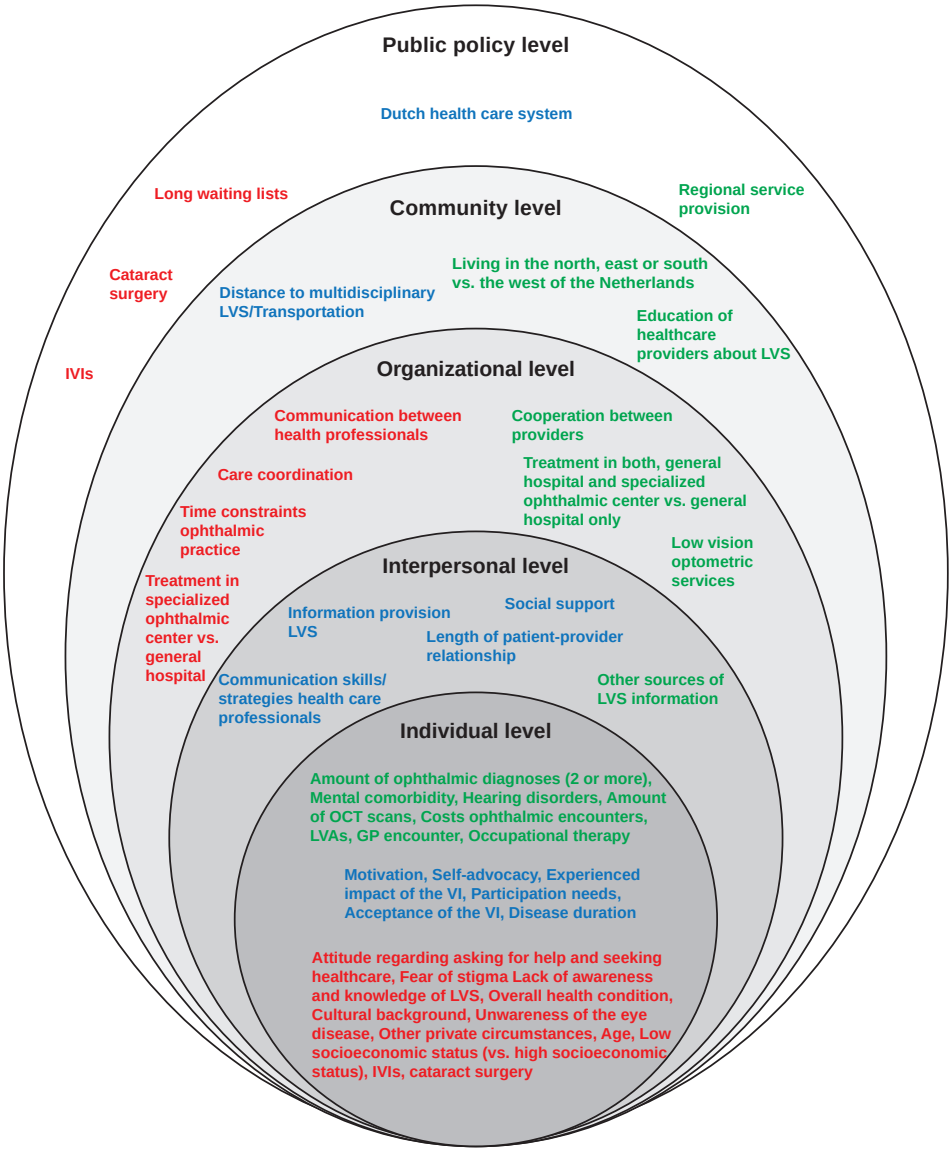

FIGURE 1. Social Ecological Model with results of this thesis.

Green: facilitator, red: barrier, blue: facilitator and barrier
Abbreviations: GP, general practitioner; IVIs, intravitreal injections; LVAs, low vision aids; OCTs, optical coherence tomography scans; VI, visual impairment

METHODOLOGICAL CONSIDERATIONS

The studies described in this thesis have both strengths and limitations. In the following the main methodological considerations of this thesis will be discussed.

Mixed methods, data triangulation and insights from high-income countries

By using both qualitative (***Chapter 2***) and quantitative (***Chapter 3-6***) research methods, we were able to gather a deep and a broad understanding with respect to barriers and facilitators in the referral pathways to LVS. In ***Chapter 2***, patients and different types of healthcare professionals shared their experiences and views on barriers and facilitators on multidisciplinary LVS access, which enabled us to get insight into the 'why' and 'how'. By examining the patients' as well as the healthcare professionals' perspective, we also triangulated our findings, which enhanced credibility.[2] In ***Chapter 3-6***, on the basis of healthcare claims data, we were able to identify sociodemographic, clinical and contextual patient characteristics, as well as their general healthcare utilization, reflecting a broad range of factors related to all levels of the Social Ecological Model. Furthermore, this is one of the first studies on LVS provision based on healthcare claims data in two high-income countries, a part of which from a high-income country with national LVS provision and high financial coverage via health insurance. Insights from this thesis may serve as a comprehensive and valuable foundation for informing health policy and practice, and may guide international researchers to conduct research with similar methodology.

Sample size, representativeness and generalizability

A strength of this thesis is the utilization of large population based datasets (Vektis C.V. and CoRe-Net), each of which included data based on a four-year period. This did not only lead to large sample sizes, which enhanced statistical power of the results, but we were also able to investigate barriers and facilitators in the referral pathways to multidisciplinary LVS on a nationwide level based on actual delivered reimbursable healthcare. This in turn, enhanced representativeness and generalizability of our findings. Besides that, the dataset used in ***Chapter 3-5*** contained a sample out of a database of almost all Dutch citizens (99% of 17.5 million), which is unique in comparison to similar databases in other countries, where claims databases often only reflect certain regions and/or only include specific health insurers. Furthermore, the CoRe-Net dataset reflected data of the years 2014-2017 of four large German insurers, including approximately half of the insured inhabitants of the city of Cologne (~1 million), which also contributed to representativeness (***Chapter 6***).

However, there are also some methodological aspects that may have limited the representativeness and generalizability of the results of this thesis.

Our findings reflect the Dutch (***Chapter 2-5***) and the German (***Chapter 6***) healthcare context, respectively. Considering the internationally varying LVS referral practices and funding systems, results may not be applicable to other countries.

Although we were able to include quite heterogeneous study populations for both professionals and patients with respect to age, sex, years of work experience (professionals), disease duration and type of referral (patients) in ***Chapter 2***, which enhanced transferability of our findings, the perspective of patients that would have benefited from multidisciplinary LVS, but did not receive that care, is missing. Therefore, important barriers in multidisciplinary LVS access may not have been identified. However, by including the perspective of professionals in ***Chapter 2*** and with our studies described in ***Chapter 4*** *and* ***5***, we believe we were able to shed some light on this perspective as well.

Furthermore, we used 2015-2018 data in ***Chapter 3-5*** and 2014-2017 data in ***Chapter 6***. As a consequence, results might not fully apply to the current LVS provision in each of the countries the studies referred to. The reason for using data of these time periods is that this was the only available data at the time of application. In addition, for the studies that related to the Dutch context (***Chapter 3-5***), claims data before 2015 were not available as multidisciplinary LVS then fell under another law, the AWBZ. The referral guideline of the Dutch Society of Ophthalmology has been revised three times since 2004.[3-5] Between the 2015 and 2018 data time-points, the second version of the referral guideline was in effect (2011).[4] Although it was revised as of 2020, it did not change fundamentally regarding the visual impairment criteria. This also applies to regulations for LVA prescriptions that were valid between 2014-2017 in Germany *(**Chapter 6**)*. They did not change essentially after 2017. Consequently, the findings from this thesis are expected to be relevant for the current Dutch LVS referral guideline and German regulations for LVA prescription.

Another limitation is the fact that we could only include patients who had been treated and received healthcare covered by health insurance (***Chapter 3-6***). Consequently certain subgroups within these study populations and the actual healthcare received by each of the study populations, might be underrepresented. For example, in ***Chapter 5***, with respect to the reference group, only patients who were treated by their ophthalmologist in the period of four years could be included. This also holds true for ***Chapter 6***, where LVA provision might be underestimated by the fact that we could only include LVS funded by health insurance. Additionally, with respect to ***Chapter 3-6***, data reflected individuals who actually received LVS after referral or after receiving a prescription (for LVAs). As a result, we did not have insight into the number of people who were referred or received a prescription but did not receive LVS.

Furthermore, data used in ***Chapter 3-5*** related to the Dutch Health Insurance Act. Consequently, other types of multidisciplinary LVS, such as long-term multidisciplinary LVS, specialized outpatient support, daytime activities and/or short-term stays is missing in our data, since these are financed according to other laws (e.g., Social Support Act (Wet Maatschappelijke Ondersteuning, WMO), Long-term Care Act (Wet Langdurige Zorg, WLZ)). In ***Chapter 4 and 5***, for patients who were 18 years old in 2018 and therefore younger than 18 between 2015 and 2017 (<1.3% of N=574,262), results for mental comorbidity might be

underestimated as well. In the Netherlands, mental healthcare for children up to 18 years is financed under the national youth law. However, as it only concerns a small percentage, it is expected to have little influence on the results. ***Chapter 3-5*** focused on multidisciplinary LVS, excluding for-profit low vision optometry, which underestimates the full provision of LVS in the Netherlands. The reason for not including for-profit low vision optometry was that it was not adequately represented in the claims data, i.e. it could not be distinguished from the broader type of optometry in the Netherlands, which does not include LVAs. Besides that, we also did not classify LVAs as multidisciplinary LVS, although they are mainly prescribed by multidisciplinary LVS and low vision optometrists, because we were uncertain about its completeness and usability when obtaining the data. As a result, this might also have limited the generalizability of our findings to the full LVS study population in the Netherlands.

Validity

Recall bias in ***Chapter 2*** might have affected validity of our results. Patients were asked to retrospectively tell about their views on and experiences with referral to LVS. Furthermore, we eventually included patients who had been referred between 8 months and 6 years ago, because it was difficult to meet the criterion of referral 'not longer than 6 months ago', partly because of the corona pandemic in 2020 and 2021. However, patients had been referred with a median of 0.75 years before the moment the interviews took place (year range, 0.2-6) and 64% of the patients were referred not longer than 1 year ago. Therefore, the larger part of our data may be relatively free from the influence of recall bias.

Furthermore, the purpose of healthcare claims data is to facilitate reimbursement of healthcare costs from health insurers. As such, they are not designed for research, but for administrative intentions, which may have limited the validity of the results of this thesis. Coding errors in healthcare claims data are a common shortcoming, possibly due to human error and complexity of coding systems.[6] Internal and external validation can be used to enhance validity in research based on claims data. However, while there are studies that investigated the external validity of Dutch healthcare claims data in a cardiac population[7] and a nephrology population[8] with very good to moderate results, respectively, there are no studies that investigated the validity of Dutch healthcare claims data in an ophthalmic population. As it would have exceeded the limits of this thesis, we neither internally nor externally validated diagnoses in ***Chapter 3-5***. However, in ***Chapter 6***, we validated ophthalmic diagnoses internally with known validation methods based on German healthcare claims data for other diagnoses.[9,10]

Moreover, certain information was missing in the healthcare claims data, such as the severity of the eye disease and visual functioning. This meant that we could not examine the role of visual acuity and/or visual field defects in the referral pathways to LVS (***Chapter 3-6***), even though it has been found to be an essential predictor for LVS access

in literature before.[11] Additionally, in ***Chapter 4 and 5***, we could not base the selection of the reference group on patients' severity of the visual impairment. However, we believe we have mitigated this bias, by selecting diagnosis groups of eye diseases for the reference group that are most likely to cause visual impairment in high-income countries.

IMPLICATIONS FOR POLICY AND CLINICAL PRACTICE

Based on the results from the studies included in this thesis, we provide several implications and recommendations for policy and clinical practice.

Patient groups that should receive special attention by policy makers and clinical practice

In this thesis, certain subgroups of patients have been identified, to whom referring eye care professionals to LVS and LVS policy makers should pay special attention. These subgroups might be particularly at risk of experiencing barriers in their referral pathway to LVS or may influence LVS provision. We recommend that special attention is needed for patients who lack self-advocacy, who have a low SES, and who are of older age, who live in rural areas and who live further away from a multidisciplinary LVS center when considering referral (***Chapter 2-4***). Focus should be also on patients with mental, physical and/or ocular comorbidity.

This thesis showed that patients who lack self-advocacy may face extra barriers to LVS access as they may lack the skills to express their multidisciplinary LVS needs and to ask for help (***Chapter 2***). Patients of older age may refuse referral because of not wanting to ask for help and/or professionals might think less about LVS in older patients. Hence, active information provision about, and referral to multidisciplinary LVS of these patient groups by referring healthcare professionals, especially ophthalmologists and optometrists, is of great importance. As reflected earlier in this chapter, informing the patient's social network might facilitate access and professionals should encourage patients to take a trusted person to medical encounters, which is also already included in the Dutch LVS referral guideline as a recommendation. Besides that, communication aids for patients in encounters, for example by using Question Prompt Lists, may facilitate them, especially those who lack self-advocacy, in expressing their needs.[12] This in turn may enhance patient participation and LVS information provision.

Although ***Chapter 3*** showed that multidisciplinary LVS patients mostly had a low or middle high SES, ***Chapter 4*** revealed that low SES lowered the odds of receiving multidisciplinary LVS. People with low education, employment and/or income are at higher risk of developing visual impairment,[13] which might explain the results from ***Chapter 3***. However, the compulsory deductible that patients need to pay for the first 385 Euro for healthcare within the basic statutory health insurance, among which multidisciplinary LVS, might explain that patients with low SES experience hinder in accessing these services. The monthly contributions of a maximum of 107 EUR that people with low income can receive to compensate the potentially high healthcare costs, might not be sufficient to diminish this barrier. Multidisciplinary LVS centers and policy makers should consider alternative financial contributions or regulations to ensure that patients with LVS needs and low SES receive the care they require.

Furthermore, special attention should be given to patients that live further away from a multidisciplinary LVS center and to elderly patients in rural areas, considering the expected rise in the number of people aged 65 years or older by 2035 in these regions. Healthcare professionals may lower the barrier for these patient groups by informing them about taxi services for elderly people and individuals with disabilities offered by Dutch municipalities and/or by encouraging them to seek help with transportation by their surroundings, as some may feel reluctant to do so (***Chapter 2***). It should be noted, however, that compared to other countries, geographical coverage of LVS is extensive and distances to LVS are short in the Netherlands, making LVS still relatively easily accessible. As seen in ***Chapter 4***, the majority of the multidisciplinary LVS users and nonusers (77%) lived within 20 km of a multidisciplinary LVS center, which is likely to be applicable to the whole of the Netherlands. Accordingly, distance and rurality might be points of interest in the referral pathways of LVS for policy makers in the Netherlands, but are strengths compared to countries with lower population density and less geographical coverage of LVS.

Patients with mental, physical and/or ocular comorbidity are patient groups that should also receive special focus by policy and clinical practice. Although results of our thesis showed that having mental comorbidity facilitates receiving multidisciplinary LVS, results also indicated that a substantial number of patients do not receive mental healthcare (***Chapter 5***). Hence, policy makers and providers should be aware of mental health complaints in patients and refer them if necessary to mental healthcare institutions or multidisciplinary LVS that offer mental healthcare interventions. An example of such an intervention is the evidence-based and cost-effective stepped care intervention for people with depression and anxiety,[14] which has already been implemented at some Dutch LVS centers. Policy makers should further focus on developing and providing mental healthcare interventions for people with visual impairment.

With respect to physical comorbidity as barrier or facilitator in the referral pathways to LVS, sometimes contrasting results were found in this thesis. On the one hand multidisciplinary LVS patients were more likely to have physical comorbidity between 2015-2018 (***Chapter 3***), on the other hand physical comorbidity was found to lower the odds for receiving multidisciplinary LVS (***Chapter 4***). In ***Chapter 5***, we concluded that the negative independent association found between physical comorbidity and receiving multidisciplinary LVS might not be important to suggest policy changes, as physical comorbidity is high in people with visual impairment by definition and most of the study population had physical comorbidity. Moreover, patients who had ocular-comorbidity and who had a comorbid hearing disorder were more likely to receive multidisciplinary LVS (***Chapter 4***). These results taken together might indicate that patients that are seen at multidisciplinary LVS centers are (getting more) complex due to physical, sensory and/or ocular comorbidity.

Fewer or future LVS needs in patients with visual impairment?

Findings from this thesis might indicate that patients with visual impairment might have fewer LVS needs or may have them later due to the benefits of treatment with intravitreal injections and/or cataract surgery (***Chapter 3 and 4***). Another development that should be mentioned that might have led to a decreased LVS need is the worldwide integration of modern technology and assistive devices in the daily lives of people with visual impairment.[15,16] Since the early twenty-first century there has been a continued development of smartphones and tablets providing built-in features and applications that help people with a visual impairment in activities in daily living, mobility and orientation, social interaction and communication. Support previously provided by LVS may now be partly provided by assistive devices. Furthermore, a generation is now growing up who knows no better than the existence of modern technologies, meaning that they have much more familiarity and ease of use than the generations before. Besides that, new developments, such as artificial intelligence, will possibly lead to more and better support of people with visual impairment by modern technologies, causing people to become even less dependent on LVS support. Lastly, new drugs for geographic atrophy, an advanced form of age-related macular degeneration, might lower LVS needs in future as well. The very first drugs Syfovre (pegcetacoplan) and Izervay (avacincaptad pegol) for treating geographic atrophy were recently (2023) approved by the US Food and Drug Administration (FDA) for clinical use.[17,18] Although the long-term implications of these medications are not yet known and the drugs are not yet approved in Europe, trial results showed that the new treatments can slow down or halt the rate of progression.[19-21] This might delay the emergence of LVS needs in high-income countries, such as the Netherlands and Germany, as well.

Adequate and timely LVS information provision is necessary, as well as continued attention for referral to LVS by referring eye care professionals

Chapter 3 showed that there was a downward trend of 15% in the number of patients that received multidisciplinary LVS between 2015 and 2018 in the Netherlands, but on average, 17,700 patients per year received non-profit multidisciplinary LVS covered by health insurance in this period. This is approximately 5% of the estimated 367,000 people with a visual impairment in the Netherlands. As this thesis excluded for-profit low vision optometry and LVS that are not funded by health insurance, such as some specific LVAs that are not reimbursed or LVS falling under other types of care legislation, it is difficult to give a precise estimate of the number of people who receive LVS annually in the Netherlands based on these results. For-profit low vision optometry institutions estimate that 22,000 patients receive LVS annually (personal communication), which includes check-up appointments, new patients and healthcare that is not reimbursed by health insurance. This would mean that annually approximately 39,700 (~11%) patients receive

some form of LVS, whether non-profit or for-profit, but excluding LVS covered by the 'WMO' or 'WLZ'.

In ***Chapter 2***, most referring professionals (ophthalmologists and optometrists) stated to regularly inform and to refer patients to multidisciplinary LVS. However, results also revealed that ophthalmologists do not always have attention for multidisciplinary LVS referral in ophthalmic encounters. Patients that are informed late or elsewhere and/or who do not see their ophthalmologist, partly seem to find their way to multidisciplinary LVS anyways (***Chapter 2 and 4***). Patients' motivation seem to be partly influenced by lack of knowledge or awareness about multidisciplinary LVS (***Chapter 2***). Communication skills and strategies in line with effective patient-provider communication and a patient-centered approach seem to facilitate multidisciplinary LVS access (***Chapter 2***).

These results stress the importance for adequate and timely information provision of patients about and attention for referral to LVS in the Netherlands. Consequently, we recommend to educate and train professionals in how en when to address LVS, including communication skills training. This is already partly included in the curriculum of the ophthalmologists training program through education on low vision and blindness in collaboration with multidisciplinary LVS centers as well as advised in the Dutch LVS referral guidelines. In addition, it may be beneficial for local LVS centers to regularly inform ophthalmologists about LVS and developments in service provision, and giving them advice on individual referral behavior. This may help to promote a dialogue between the different providers in the different regions, to foster trust and understanding among each other, which in turn may enhance collaboration and referral procedures. It may also help ophthalmologists to be more aware of the fact that LVS is part of patients' healthcare trajectory and that it can run parallel to the curative care trajectory provided by the ophthalmologist. Patient associations and other healthcare professionals than ophthalmologists and optometrists (e.g., nurses, ophthalmic assistants), who appear to be important other sources of LVS information for patients (***Chapter 2***), should be regularly informed as well. Furthermore, LVS organizations should continue to provide LVS advice and information online. It may also be beneficial for LVS organizations to provide communication about a patients' referral and patient outcomes of having received LVS to ophthalmologists as feedback and to enhance awareness (***Chapter 2***).

Awareness about LVS in referring eye care professionals and referral procedures may be stimulated by clinical decision support tools and vision-related patient reported outcome measures (PROMs). Electronic health record-based clinical decision support tools are integrated in electronic health records, which assist healthcare professionals in decision-making for diagnoses and treatment based on medical patient data stored in the electronic health records.[22,23] Their aim is to optimize healthcare delivery. Research has shown that electronic health record-based clinical decision support systems are promising to improve LVS referral procedures and utilization of LVS.[24,25]

PROMs are questionnaires that are used in clinical practice to investigate patients' needs, symptoms, disease burden, quality of life and to evaluate and monitor treatment effectiveness from the patient's perspective.[26-28] They may also support healthcare professionals in clinical decision making, patients in expressing their needs and facilitate effective patient-provider communication.[27,29] Vision-specific PROMs were found to be assistive for professionals to have more attention for the patient perspective and to give insights into the impact of an eye disease on patients' quality of life.[30] Accordingly, integrating them in the ophthalmic practice may facilitate referral to LVS. It may further help to diminish barriers for earlier mentioned patient groups that should get special focus by policy makers and clinicians, and for patient groups that lack care coordination, for example those who are in treatment with intravitreal injections and are therefore at risk of being overlooked for LVS referral.

LVS provision in high-income countries

As stated earlier, there are different LVS and healthcare funding systems in high as well as low-income countries. Although we gained insight into LVS provision in two neighboring high-income countries in Europe, there are even significant differences in their systems, making them and the results of the different studies of this thesis difficult to compare.

However, some of the results of this thesis and given implications for policy and clinical practice might be applicable to high-income countries in general, by taking into account the principles of rehabilitation as formulated by the WHO and the UN Office of the High Commissioner for Human Rights, namely availability, accessibility, acceptability and quality.[31,32] 'Availability' refers to the availability of services. 'Accessibility' refers to non-discrimination, physical accessibility, economical accessibility (affordability) and information accessibility. 'Acceptability' refers to respect of services for medical ethics, as well as gender-sensitivity and cultural appropriateness. The principle 'quality' refers to good quality of services, which are scientifically and medically appropriate and include trained health professionals.

Results of this thesis imply that although services may be available in high-income countries, physical, economical and information accessibility might still be a challenge. Therefore, high-income countries should generally focus on financial regulations to ensure access for patients with all types of SES, stimulating self-advocacy in patients, and adequate and timely LVS provision. The implications with respect to fewer or later LVS needs in patients due to the benefits of treatment with intravitreal injections and/or cataract surgery, modern technology and new drugs for geographic atrophy, might be applicable to high-income countries in general as well. In addition, findings from this thesis and the description of the different LVS systems may provide policy makers and clinicians from other high-income countries with insights to examine referral pathways and LVS provision.

RECOMMENDATIONS FOR FUTURE RESEARCH

Based on the five studies included in this thesis and based on previous research, several recommendations for research related to LVS referral and factors influencing the referral pathways to LVS in high-income countries can be provided.

Investigate the role of for-profit low vision optometrists in Dutch LVS provision

In this thesis, the studies based on the Dutch LVS context mainly focused on factors influencing the referral pathways to non-profit multidisciplinary LVS, including non-profit low vision optometry, but excluding for-profit low vision optometry (***Chapter 2-5***). ***Chapter 2*** gave insight into the role of low vision optometric services provided at hospital ophthalmology departments in the referral to multidisciplinary LVS, which were identified as facilitators in the referral pathways to multidisciplinary LVS. However, the role of low vision optometrists who provide their services at specialized optical shops and/or at patients' homes are underexposed. Therefore, future research should further examine the role of for-profit low vision optometry provided at the different locations in the referral of patients to multidisciplinary LVS. Furthermore, insight into predictors for referral to low vision optometrists would be beneficial.

Evaluate the feasibility and effectiveness of clinical decision support systems and communication aids for patients in the Dutch LVS context

As noted earlier in this chapter, clinical decision support systems and communication aids for patients may help to facilitate LVS referral procedures. However, research on the feasibility and effectiveness of such tools in the LVS context is scarce.[24,25] Currently, a communication aid for patients with macular degeneration is being developed.[33] As far as we know, there are no studies on communication aids for other ophthalmic patient groups and no studies on clinical decision support systems in the Dutch context. Accordingly, more research on these topics would be valuable.

Conduct validation studies on healthcare claims data for ophthalmic diagnoses

More insight into the validity of Dutch and German healthcare claims data for identifying patients with ophthalmic diagnoses is warranted. As noted earlier, for research based on healthcare claims data it is recommended to examine and/or report the validity of diagnosis codes for the selection of study populations, because of the administrative nature of the data and possible inaccuracy of registered diagnoses codes.[34] However, to our knowledge, none of these studies were conducted in the Netherlands or Germany for ophthalmic diagnoses. It would be valuable to know how accurate and representative the data actually are. Furthermore, with more insights on this topic researchers will be able to evaluate the sensitivity for the estimation of prevalence of certain ophthalmic diseases

in the general population based on healthcare claims data, which will strengthen the methodology for future research.

Include visual function information

Because of using administrative healthcare claims data in ***Chapter 3-6***, visual function information, e.g., visual acuity, visual field defect and type of ophthalmic diagnosis (according to ICD-10) was not available, as the latter were summarized by diagnosis-treatment combination codes. Future studies on factors influencing the referral pathways to LVS in the Dutch and German context should include this clinical information to examine its association with LVS access. By linking healthcare claims data with other data sources, such as the National Basic Hospital Care Registration (Landelijke Basisregistratie Ziekenhuiszorg (LBZ))[35], the Health Survey[36] and the Health Monitor[37] of Statistics Netherlands, electronic health record data, or longitudinal prospective cohort registries (e.g., Lifelines,[38] LASA[39]) we might be able to retrieve more data on visual functioning in future research. Furthermore, future studies on predictors of receiving LVS should strive to select patients for the reference group based on their visual acuity to be sure to include patients with a visual impairment.

Investigate the role of opticians and optometrists in the referral pathways to Dutch LVS

Opticians in the Netherlands perform vision screenings to assess visual acuity and help individuals to find suitable eyewear. People may visit an optician in an optical store if they experience deteriorating and/or blurred vision, or if they already wear glasses and wish to have their eyes examined. Opticians also help people to find eyewear based on prescriptions by optometrists and ophthalmologists. If more care is needed, patients should be referred to an (general) optometrist, who conducts eye health examinations and determines if more care is needed from an ophthalmologist. Optometrists also work in optical stores, where they conduct eye health examinations and prescribe glasses and lenses. They also sometimes offer special encounters for checkups for diabetes and glaucoma patients and for patients with other non-acute eye complaints. As little is known about the role of opticians and the general type of optometrists and possible barriers and facilitators in the referral pathways to LVS, this might be interesting to examine in future research.

Further investigate LVS provision in Germany and in other (high-income) countries

Chapter 6 gave insight into LVA provision funded by health insurance in an urban setting in Germany. However, to get a comprehensive understanding of how LVS provision and referral to LVS looks like, future research should focus on further investigating LVS provision in Germany in urban, as well as rural areas. It would be also interesting to examine LVS provision other than LVAs, such as psychological therapy and training and support in

mobility and orientation and activities of daily living. Furthermore, gaining more insight in the distribution of LVS provision among the different providing institutions, such as ophthalmology departments in hospitals/eye clinics, optician practices, social services/ social work institutions and patient organizations, as well as understanding how patients with a visual impairment access them, would be valuable. Additionally, it is recommended to examine how patients experience the funding of LVS, as they are only partially funded for example by health, retirement and accident insurance. More insight might help to diminish possible barriers and to optimize current LVS provision.

Furthermore, research should focus on comparing more (high-income) countries with respect to LVS provision to find out best practices.

CONCLUSION

In conclusion, this thesis has shown that there are various facilitators and barriers on individual, interpersonal, organizational, community and public policy level that influence the referral pathways to LVS in high-income countries. For the Dutch context, vulnerable subgroups have been identified that may experience extra barriers in multidisciplinary LVS receipt: patients who lack self-advocacy, who have a low SES, and who are of older age, who live in rural areas and who live further away from a multidisciplinary LVS. The results indicate that eye care professionals and policy makers should especially focus on adequate and timely information provision and continued attention for LVS referral. Additionally, tools such as PROMs, clinical decision support systems and patient communication aids might help improving suboptimal referral pathways for these patients. Furthermore, eye care professionals and policy makers should pay attention to patients with mental complaints, refer these patients to mental healthcare institutions or multidisciplinary LVS and provide mental healthcare interventions. At the same time, not all patients eligible for multidisciplinary LVS seem to have multidisciplinary LVS needs and findings imply that patients may have fewer LVS needs due to treatments for retinal exudative disease, cataract surgery and modern technology, which may help them manage themselves for longer. Investigating the role of low-vision optometrists, opticians and general optometrists in the referral pathways to LVS in future research, may allow better understanding of the factors influencing receipt of Dutch LVS.

For the German context, our findings provided a starting point for examining LVS provision in Germany, which should be further examined in future research.

With these insights, this thesis has contributed to a better understanding of current referral procedures and LVS provision in two high-income countries. With the given advices, eye care professionals and policy makers will be equipped to ensure that individuals with LVS needs receive the right care at the right moment, and at the right place.

REFERENCES

1. McLeroy KR, Bibeau D, Steckler A, Glanz K. An ecological perspective on health promotion programs. *Health Educ Q.* 1988;15(4):351-77.
2. Farmer T, Robinson K, Elliott SJ, Eyles J. Developing and Implementing a Triangulation Protocol for Qualitative Health Research. *Qual Health Res.* 2006;16(3):377-94.
3. Nederlands Oogheelkundig Gezelschap. Richtlijn Verwijzing van slechtzienden en blinden: Boer MR de, Jansonius N, Langelaan M, en Rens GHMB van (red). Van Zuiden Communications bv. Alphen aan de Rijn. 2004.
4. van Rens GHMB, Vreeken HL, van Nispen RMA. Richtlijn visusstoornissen revalidatie en verwijzing [Guideline vision disorders: rehabilitation and referral] 2011 [cited 2020 Sep 20]. Available from: http://www.vivis.nl/wp-content/uploads/2019/10/Richtlijn-visusstoornissen-revalidatie-en-verwijzing.pdf.
5. Nederlands Oogheelkundig Gezelschap. Visuele beperkingen - verwijzing en revalidatie [Vision disorders: referral and rehabilitation] 2020 [cited 2022 Jan 8]. Available from: https://richtlijnendatabase.nl/richtlijn/visuele_beperkingen_-_verwijzing_en_revalidatie/verwijzing_voor_revalidatie_bij_visuele_beperkingen.html.
6. Stein JD, Lum F, Lee PP, Rich WL, 3rd, Coleman AL. Use of health care claims data to study patients with ophthalmologic conditions. *Ophthalmology.* 2014;121(5):1134-41.
7. Eindhoven DC, van Staveren LN, van Erkelens JA, Ikkersheim DE, Cannegieter SC, Umans VAWM, et al. Nationwide claims data validated for quality assessments in acute myocardial infarction in the Netherlands. *Neth Heart J.* 2018;26(1):13-20.
8. van Oosten MJM, Brohet RM, Logtenberg SJJ, Kramer A, Dikkeschei LD, Hemmelder MH, et al. The validity of Dutch health claims data for identifying patients with chronic kidney disease: a hospital-based study in the Netherlands. *Clin Kidney J.* 2020;14(6):1586-93.
9. Köster I, Mehl C, Siegel A, Graf E, Stelzer D, Farin-Glattacker E, et al. [Operationalization of Quality Indicators with Routine Data Using the Example of the Evaluation of "Integrated Care Healthy Kinzigtal"]. *Gesundheitswesen.* 2021;83(S 02):S87-s96.
10. Köster I, Mehl C, Siegel A, Graf E, Stelzer D, Farin-Glattacker E, et al. [Correction: Operationalization of Quality Indicators with Routine Data Using the Example of the Evaluation of "Integrated Care Healthy Kinzigtal"]. *Gesundheitswesen.* 2021;83(S 02):e58.
11. Goldstein JE, Guo X, Boland MV, Swenor BK. Low Vision Care - Out of Site. Out of Mind. *Ophthalmic Epidemiol.* 2020;27(4):252-8.
12. Sansoni JE, Grootemaat P, Duncan C. Question Prompt Lists in health consultations: A review. *Patient Educ Couns.* 2015;98(12):1454-64.
13. Whillans J, Nazroo J. Social Inequality and Visual Impairment in Older People. *J Gerontol B Psychol Sci Soc Sci.* 2016;73(3):532-42.
14. van der Aa HP. Depression and anxiety in visually impaired older adults: cost-effectiveness of stepped care. 2016.
15. Hersh MA, Johnson MA. Assistive technology for visually impaired and blind people: Springer; 2008.
16. Aqel MOA, Issa A, Elsharif AA, Ghaben S, Alajerami YSM, Khalaf H, et al., editors. Review of Recent Research Trends in Assistive Technologies for Rehabilitation. 2019 International Conference on Promising Electronic Technologies (ICPET); 2019 23-24 Oct. 2019.
17. Antonio-Aguirre B, Arevalo JF. Treating patients with geographic atrophy: are we there yet? *Int J Retina Vitreous.* 2023;9(1):72.
18. Csaky KG, Miller JML, Martin DF, Johnson MW. Drug Approval for the Treatment of Geographic Atrophy: How We Got Here and Where We Need to Go. *Am J Ophthal.* 2024;263:231-9.

19. Heier JS, Lad EM, Holz FG, Rosenfeld PJ, Guymer RH, Boyer D, et al. Pegcetacoplan for the treatment of geographic atrophy secondary to age-related macular degeneration (OAKS and DERBY): two multicentre, randomised, double-masked, sham-controlled, phase 3 trials. *Lancet.* 2023;402(10411):1434-48.
20. Jaffe GJ, Westby K, Csaky KG, Monés J, Pearlman JA, Patel SS, et al. C5 Inhibitor Avacincaptad Pegol for Geographic Atrophy Due to Age-Related Macular Degeneration: A Randomized Pivotal Phase 2/3 Trial. *Ophthalmology.* 2021;128(4):576-86.
21. Khanani AM, Patel SS, Staurenghi G, Tadayoni R, Danzig CJ, Eichenbaum DA, et al. Efficacy and safety of avacincaptad pegol in patients with geographic atrophy (GATHER2): 12-month results from a randomised, double-masked, phase 3 trial. *Lancet.* 2023;402(10411):1449-58.
22. Lobach D, Sanders GD, Bright TJ, Wong A, Dhurjati R, Bristow E, et al. Enabling health care decisionmaking through clinical decision support and knowledge management. *Evid Rep Technol Assess (Full Rep).* 2012(203):1-784.
23. Sim I, Gorman P, Greenes RA, Haynes RB, Kaplan B, Lehmann H, et al. Clinical decision support systems for the practice of evidence-based medicine. *J Am Med Inform Assoc.* 2001;8(6):527-34.
24. Guo X, Swenor BK, Smith K, Boland MV, Goldstein JE. Developing an Ophthalmology Clinical Decision Support System to Identify Patients for Low Vision Rehabilitation. *Transl Vis Sci Technol.* 2021;10(3):24.
25. Guo X, Boland MV, Swenor BK, Goldstein JE. Low Vision Rehabilitation Service Utilization Before and After Implementation of a Clinical Decision Support System in Ophthalmology. *JAMA Netw Open.* 2023;6(2):e2254006.
26. Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: a systematic review of qualitative research. *BMJ Qual Saf.* 2014;23(6):508-18.
27. Makhni EC, Hennekes ME. The Use of Patient-Reported Outcome Measures in Clinical Practice and Clinical Decision Making. *J Am Acad Orthop Surg.* 2023;31(20):1059-66.
28. Kyte DG, Calvert M, van der Wees PJ, ten Hove R, Tolan S, Hill JC. An introduction to patient-reported outcome measures (PROMs) in physiotherapy. *Physiotherapy.* 2015;101(2):119-25.
29. Yang LY, Manhas DS, Howard AF, Olson RA. Patient-reported outcome use in oncology: a systematic review of the impact on patient-clinician communication. *Support Care Cancer.* 2018;26(1):41-60.
30. Rausch-Koster TP, van der Aa HPA, Verbraak FD, van Rens G, van Nispen RMA. Perspectives of Patients and Professionals on Implementing a Computer Adaptive Vision-Related Quality of Life Outcome (CAT-EyeQ) in Clinical Practice. *Transl Vis Sci Technol.* 2024;13(3):6.
31. World Health Organisation (WHO). International Standards for Vision Rehabilitation: report of the International consensus Conference 2017.
32. Office of the United Nations High Commissioner for Human Rights World Health Organization. The right to health: Fact sheet no. 31: United Nations Geneva; 2008 [cited 2024 May 17]. Available from: https://www.ohchr.org/sites/default/files/Documents/Publications/Factsheet31.pdf.
33. Netherlands Institute for Health Services Research. Gesprekshulpmiddel 'Praten Over Maculadegeneratie' ontwikkelen en toetsen [Developing and testing the communication tool 'Talking About Macular Degeneration'] n.d., [cited 2024 May 5]. Available from: https://www.nivel.nl/nl/project/gesprekshulpmiddel-praten-over-maculadegeneratie-ontwikkelen-en-toetsen.
34. van Walraven C, Bennett C, Forster AJ. Administrative database research infrequently used validated diagnostic or procedural codes. *J ClinEpidemiol.* 2011;64(10):1054-9.

35. Stichting Dutch Hospital Data. Ontdek de mogelijkheden van de LBZ [Discover the possibilities of the LBZ] 2024 [cited 2024 May 5]. Available from: https://www.dhd.nl/producten-diensten/registratie-data/ontdek-de-mogelijkheden-van-de-lbz.
36. Statistics Netherlands. Gezondheidsenquête [Health Survey] 2024 [cited 2024 May 5]. Available from: https://www.cbs.nl/nl-nl/deelnemers-enquetes/personen/overzicht/gezondheidsenquete.
37. Statistics Netherlands. Gezondheidsmonitor [Health Monitor] 2024 [cited 2024 May 5]. Available from: https://www.cbs.nl/nl-nl/onze-diensten/methoden/onderzoeksomschrijvingen/korte-onderzoeksbeschrijvingen/gezondheidsmonitor#:~:text=De%20Gezondheidsmonitor%20is%20een%20samenvoeging,van%20alle%2028%20GGD'en.
38. Lifelines. Over ons [About us] [cited 2024 May 5]. Available from: https://www.lifelines.nl/over-ons.
39. LASA. LASA main study 2023 [cited 2024 May 5]. Available from: https://lasa-vu.nl/en/lasa-main-study/.

ADDENDUM

DUTCH SUMMARY – NEDERLANDSE SAMENVATTING

Onomkeerbaar verlies van gezichtsvermogen kan een enorme impact hebben op het leven van betrokkenen, met gevolgen voor dagelijkse activiteiten, mentaal welzijn, arbeidsparticipatie en kwaliteit van leven. Wanneer door deze gevolgen mensen zich onvoldoende meer redden, kunnen oogartsen (of soms ook andere medisch specialisten) in Nederland volgens de richtlijn 'visusstoornissen, revalidatie en verwijzing' verwijzen naar multidisciplinaire visuele revalidatiezorg bij drie landelijke expertiseorganisaties Koninklijke Visio, Bartiméus en de Robert Coppes Stichting. Visuele revalidatie richt zich op het omgaan met de visuele beperking en het verbeteren van het visueel functioneren, zelfstandigheid en participatie. Naast het aanmeten van loepen en andere hulpmiddelen, zoals een herkenningsstok of speciale navigatiehulpmiddelen of computersoftware, bieden de revalidatiecentra ook ambulante zorg. Voorbeelden zijn ergotherapie voor aanpassingen in huis en verlichting, training in dagelijkse activiteiten, mobiliteit en computer- en smartphonegebruik, maar ook maatschappelijk werk en psychologische of arbeidsgerelateerde ondersteuning. Oogartsen hebben naast het verwijzen naar revalidatie, de mogelijkheid om te verwijzen naar optometristen en low vision specialisten voor het aanmeten van en advies over low vision hulpmiddelen, zoals loepen en aangepaste brillen. Deze vormen van zorg, visuele revalidatie en low vision hulpmiddelen, worden internationaal ook wel Low Vision Services (LVS) genoemd, waarbij visuele revalidatiezorg, zoals aangeboden door de Nederlandse expertiseorganisaties, wordt verstaan als 'multidisciplinaire LVS'.

Eerdere studies tonen aan dat LVS kunnen helpen om de kwaliteit van leven van mensen met een ernstige visuele beperking te verbeteren. Echter, ondanks de voordelen van LVS, komt niet iedereen die daarvoor in aanmerking zou komen, bij deze zorg terecht en ontvangt deze zorg. Het is onduidelijk waarom dat zo is. Hoewel internationaal onderzoek barrières in de verwijspaden naar LVS heeft gerapporteerd, ontbreekt er een uitgebreid inzicht in de factoren die van invloed zijn op de verwijspaden naar LVS, vooral in hoge-inkomenslanden.

Tegen deze achtergrond, was het doel van dit proefschrift, de Visually Impaired Person Path (VIP-Path) studie, om factoren die van invloed zijn op de verwijspaden naar LVS in hoge-inkomenslanden in kaart te brengen. In de vijf studies die in dit proefschrift worden beschreven, zijn verschillende methodes en perspectieven gebruikt om meer inzicht te krijgen in belemmerende en bevorderende factoren in deze verwijspaden in Nederland en Duitsland. Hierbij werd rekening gehouden met het Sociaal Ecologisch Model. Het Sociaal Ecologisch Model is een model dat laat zien dat individuen in interactie staan met hun omgeving waarbij sprake is van meerdere niveaus (individueel, interpersoonlijk (tussen personen), organisatorisch, maatschappelijk- en beleidsniveau), die gedrag en gezondheid van individuen beïnvloeden.

In de eerste studie (***hoofdstuk 2***) werd het perspectief van patiënten en zorgverleners op belemmerende en bevorderende factoren voor het ontvangen van multidisciplinaire LVS onderzocht. De tweede studie richtte zich op trends, ofwel ontwikkelingen die zich over een bepaalde tijdsperiode voordoen, in het gebruik van multidisciplinaire LVS (***hoofdstuk 3***). Het doel van de derde studie (***hoofdstuk 4***) was om voorspellers voor het ontvangen van multidisciplinaire LVS in kaart te brengen. Vervolgens werd de rol van comorbiditeit, ofwel het hebben van andere aandoeningen naast de oogaandoening, verder onderzocht in de vierde studie (***hoofdstuk 5***). Terwijl de eerste vier studies betrekking hadden op Nederland, was de laatste studie gericht op het onderzoeken van trends in het gebruik van low vision hulpmiddelen in Duitsland (***hoofdstuk 6***).

Belemmerende en bevorderende factoren vanuit het perspectief van zorgprofessionals en volwassenen met een visuele beperking.

Slechts enkele studies hebben zowel vanuit het perspectief van de patiënt als van de zorgprofessional factoren in kaart gebracht die van invloed zijn op de verwijspaden van patiënten naar LVS. Bovendien ontbrak tot nu toe het perspectief van landen met een hoog inkomen. In de studie beschreven in ***hoofdstuk 2*** werden daarom 14 patiënten van 50 jaar of ouder met aandoeningen van de gele vlek (maculadegeneratie), de oogzenuw (glaucoom) en/of het netvlies als gevolg van suikerziekte (diabetische retinopathie) en 16 zorgprofessionals, waaronder oogartsen, low vision optometristen en professionals van een multidisciplinaire LVS organisatie geïnterviewd. Uit deze interviews kwamen verschillende factoren op individueel, interpersoonlijk, organisatorisch, maatschappelijk- en beleidsniveau van het Sociaal Ecologisch Model naar voren.

Op individueel niveau was de eigen motivatie vanuit de patiënten zelf zowel een belangrijke belemmerende als bevorderende factor in de verwijzing naar multidisciplinaire LVS. In lijn met gedeelde besluitvorming gaven professionals aan alleen patiënten te verwijzen die dat willen, en patiënten die in aanmerking komen voor multidisciplinaire LVS lijken een verwijzing regelmatig te weigeren. Verder werd de motivatie van patiënten beïnvloed door individuele patiëntfactoren zoals de ervaren impact van de aandoening, (gebrek aan) acceptatie van de aandoening, ziekteduur en gebrek aan kennis over het bestaan van multidisciplinaire LVS. Ook participatiebehoeften, dus de behoefte om ondanks de visuele beperking deel te nemen aan de maatschappij, en attitudes, ofwel de houding die men heeft over het verwezen worden, hadden invloed op de verwijzing zelf. Daarnaast werd het (niet) mondig zijn als patiënt vastgesteld als een belangrijke bevorderende en belemmerende factor.

Op interpersoonlijk niveau kwamen informatievoorziening over multidisciplinaire LVS en communicatievaardigheden van professionals naar voren als belangrijke belemmerende en bevorderende factoren. Terwijl de helft van de geïnterviewde patiënten aangaf dat zij zelf het initiatief namen voor hun verwijzing of dat zij niet door hun zorgverlener

waren geïnformeerd over multidisciplinaire LVS, zeiden bijna alle professionals met de bevoegdheid om te verwijzen (low vision optometristen en oogartsen) patiënten regelmatig te informeren. Bovendien gaven sommige patiënten aan laat te zijn geïnformeerd over multidisciplinaire LVS. Patiënten hadden echter niet het gevoel dat ze te laat waren verwezen, omdat de meesten van hen zelf contact hadden opgenomen met de multidisciplinaire LVS organisatie of zelf het initiatief hadden genomen tot verwijzing. Verder bleek uit de interviews met patiënten en zorgprofessionals dat communicatievaardigheden van professionals, zoals het juiste moment aanvoelen en timen om over multidisciplinaire LVS te praten en patiënten te verwijzen, patiënten actief vragen stellen over hun functioneren in het dagelijks leven, duidelijke voorbeelden gebruiken, patiënten motiveren, verwachtingen managen en informatie herhalen, de verwijzing naar multidisciplinaire LVS te kunnen bevorderen.

Het hebben van sociale steunnetwerken werd vanuit beide perspectieven benoemd als een andere relevante bevorderende factor op interpersoonlijk niveau. Sociale steun tijdens oogheelkundige afspraken, dus een naaste die meegaat, kan het vaststellen van de behoefte aan multidisciplinaire LVS van patiënten bevorderen. Daarnaast kunnen patiënten door hun sociale netwerk worden geïnformeerd over multidisciplinaire LVS en/of het sociale netwerk van de patiënt kan helpen om contact op te nemen met de multidisciplinaire LVS organisatie. Het ontbreken van een sterk sociaal steunnetwerk zou volgens de geïnterviewde professionals een belemmering kunnen vormen.

Andere bevorderende factoren die naar voren kwamen waren een langere behandelrelatie tussen patiënt en zorgverlener (interpersoonlijk niveau), communicatie tussen zorgverleners en low vision spreekuren (organisatorisch niveau), de voorlichting aan zorgverleners (maatschappelijk niveau), het Nederlandse zorgstelsel en regionale zorgverlening van multidisciplinaire LVS (beleidsniveau). Andere belemmerende factoren die in dit onderzoek naar voren kwamen zijn een korte behandelrelatie tussen patiënt en zorgverlener (interpersoonlijk niveau), gebrek aan zorgcoördinatie en tijdsdruk in de oogheelkundige praktijk (organisatorisch niveau), angst voor stigmatisering van patiënten en afstand tot multidisciplinaire LVS/gebrek aan vervoer van patiënten (maatschappelijk niveau), en het Nederlandse zorgstelsel en lange wachtlijsten voor multidisciplinaire LVS (beleidsniveau).

Trends in gebruik van multidisciplinaire LVS

In Nederland zagen we tussen 2015 en 2018 een dalende trend in het gebruik van multidisciplinaire LVS. In 2015 werd multidisciplinaire LVS voor het eerst vergoed door de zorgverzekering in plaats van via de Algemene Wet Bijzondere Ziektekosten (AWBZ). In hoofdstuk 3 van dit proefschrift worden landelijke trends tussen 2015 en 2018 in het gebruik van multidisciplinaire LVS in Nederland beschreven op basis van declaraties van zorgverzekeraars (Vektis C.V.), dus de gegevens die zorgverleners (zoals ziekenhuizen,

huisartsen of andere zorgprofessionals) indienen bij zorgverzekeraars om de kosten van geleverde zorg te vergoeden, om factoren in kaart te brengen die gerelateerd zijn aan de neerwaartse trend die we konden vaststellen. We hebben specifiek naar trends in sociaaldemografische, klinische en contextuele kenmerken, maar ook naar algemeen zorggebruik van volwassen patiënten (18+) van drie multidisciplinaire Nederlandse LVS organisaties gekeken.

Uit de resultaten bleek dat het multidisciplinaire LVS-gebruik tussen 2015 en 2018 met 15% afnam. Een mogelijke verklaring hiervoor zou kunnen liggen in een verminderd aandeel patiënten dat werd behandeld met injecties in het oog tegen vochtophoping in het netvlies en patiënten met aandoeningen van de lens binnen multidisciplinaire LVS. In lijn met onze resultaten werd een toename van deze injecties in Nederland en een toename van staaroperaties in Europa, inclusief Nederland, gezien. Dit zou erop kunnen wijzen dat meer patiënten baat hebben bij deze behandelingen en daardoor minder behoefte hebben aan multidisciplinaire LVS vanwege het positieve behandeleffect.

Bovendien lieten de resultaten zien dat patiënten die multidisciplinaire LVS ontvingen, voornamelijk 65 jaar of ouder waren, vrouw waren en oogziekten hadden die een probleem veroorzaakten in de gele vlek (macula), het deel van het netvlies waarmee je scherp kunt zien. Verder hadden patiënten meestal een lage of middelhoge sociaaleconomische status en woonden in stedelijke gebieden binnen 20 km van een multidisciplinair LVS-centrum. Patiënten die multidisciplinaire LVS kregen, ontvingen relatief veel medisch specialistische zorg voor lichamelijke klachten, dus zorg verleend in ziekenhuizen of zelfstandige behandelcentra, en geestelijke gezondheidszorg voor mentale klachten. Daarnaast hadden zij vaker lichamelijke klachten naast hun oogziekte door de jaren heen. Toekomstvoorspellingen voor Nederland geven aan dat het aandeel mensen van 65 jaar of ouder in de komende decennia met name in landelijke gebieden zal toenemen, als gevolg van vergrijzing en verhuizing van jongere mensen naar stedelijke gebieden. Daarom verdient de ongelijkheid in de toegankelijkheid van multidisciplinaire LVS extra aandacht.

Voorspellende factoren en de rol van comorbiditeit bij het ontvangen van multidisciplinaire LVS

Om meer inzicht te krijgen in belemmerende en bevorderende factoren in de verwijspaden naar LVS in hoge-inkomenslanden, hebben we onderzoek gedaan naar voorspellers voor het ontvangen van multidisciplinaire LVS in Nederland op basis van declaratiegegevens van zorgverzekeraars (***hoofdstuk 4***). We brachten de sociaaldemografische, klinische en contextuele kenmerken van patiënten in kaart en hun algemene zorggebruik. Daarnaast onderzochten we of deze kenmerken voorspellers waren.

Patiëntkenmerken die de ontvangst van multidisciplinaire LVS voorspelden waren voorschriften voor low vision hulpmiddelen, het hebben van meer oogaandoeningen tegelijk, het hebben van mentale klachten naast de oogaandoening, het ontvangen van ergotherapie, het hebben van een gehoorstoornis, behandeling in meerdere behandel-

centra, niet woonachtig zijn in het westen van Nederland (stedelijk gebied), het vaker ontvangen van optische coherentie tomografie scans van het netvlies en frequente contacten met een huisarts. Een mogelijke verklaring hiervoor was dat zorgprofessionals, zoals huisartsen, low vision optometristen en oogartsen wellicht al aandacht hebben voor de (visuele) beperking(en) van patiënten, wat op zijn beurt verwijzing en dus het ontvangen van multidisciplinaire LVS zou kunnen bevorderen.

Oudere leeftijd, lage sociaaleconomische status, het hebben van andere lichamelijke klachten naast de oogaandoening, behandeling in een zelfstandig behandelcentrum, behandeling met injecties in het oog, een staaroperatie, hogere kosten voor oogheelkundige afspraken en een grotere afstand tot een multidisciplinair LVS-centrum waren gerelateerd aan een lagere kans op het ontvangen van multidisciplinaire LVS. De belangrijkste conclusie is dat er extra aandacht moet worden besteed aan oudere patiënten, patiënten met een lage sociaaleconomische status en patiënten die verder weg wonen van een multidisciplinair LVS-centrum.

Opvallend was dat 39% van de patiënten die in 2018 gebruik maakten van multidisciplinaire LVS, in 2015-2017 geen gebruik maakten van medisch specialistische oogzorg. Dit geeft aan dat de groep patiënten die in de jaren daarvoor niet bij hun oogarts waren, toch de weg naar multidisciplinaire LVS hebben gevonden.

In de studie beschreven in ***hoofdstuk 5*** onderzochten we verder het verband tussen het hebben van mentale klachten en lichamelijke klachten naast het hebben van een oogaandoening en het ontvangen van multidisciplinaire LVS. We voerden deze studie uit tegen de achtergrond dat bevindingen uit eerder onderzoek tegenstrijdig waren met betrekking tot de rol van het hebben van meer klachten naast de oogaandoening bij het ontvangen van multidisciplinaire LVS. Zowel lichamelijke als mentale klachten bleken zowel belemmerende als bevorderende factoren te zijn. In deze studie werden vijf modellen getest met en zonder de variabelen die mogelijk het verband tussen het hebben van meer klachten tegelijk en het terecht komen bij LVS konden verstoren, zoals leeftijd, geslacht, sociaaleconomische status, woonplaats en aantal oogheelkundige diagnoses. Het model dat alle veronderstelde 'verstorende variabelen' bevatte, bleek het verband tussen mentale en lichamelijke klachten en het ontvangen van multidisciplinaire LVS het beste te beschrijven. Volgens dit model hadden patiënten met mentale klachten een hogere kans op het ontvangen van multidisciplinaire LVS in vergelijking met patiënten zonder psychische klachten nadat we voor de verstorende variabelen hadden gecorrigeerd. Bovendien hadden patiënten met lichamelijke klachten een lagere kans op het ontvangen van multidisciplinaire LVS in vergelijking met patiënten zonder lichamelijke klachten.

Onze resultaten toonden aan dat mentale klachten een bevorderende factor is voor het ontvangen van multidisciplinaire LVS. Voor lichamelijke klachten leek het tegenovergestelde te gelden. Aangezien patiënten met een visuele beperking per definitie vatbaarder zijn voor lichamelijke klachten, en de meerderheid van de studiepopulatie

lichamelijke klachten had (83%), concludeerden we dat deze bevinding minder relevant is voor veranderingen in beleid.

Verstrekking van LVS in Duitsland

Met de studie die in ***hoofdstuk 6*** wordt beschreven onderzochten we de verstrekking van LVS in Duitsland in een stedelijke omgeving, namelijk Keulen. We keken specifiek naar de verstrekking van low vision hulpmiddelen, omdat dit het enige type LVS is dat in Duitsland (gedeeltelijk) wordt gefinancierd door de zorgverzekering en wordt verstrekt binnen de context van LVS. Op basis van declaratiegegevens van vier grote wettelijke zorgverzekeraars in Keulen over een periode van 4 jaar brachten we sociaaldemografische en klinische kenmerken in kaart van personen die een voorschrift voor een low vision hulpmiddel hadden ingediend. Daarnaast brachten we trends in deze kenmerken in kaart. Het doel was inzicht te krijgen in welke personen low vision hulpmiddelen gebruiken, welke low vision hulpmiddelen worden gebruikt, en hoe vaak ze worden gebruikt.

Onze resultaten lieten zien dat tussen 2014-2017, voor of door 781 unieke personen (~0,2%) in onze studiepopulatie van 500.000 inwoners van Keulen (totale populatie ~1 miljoen) een voorschrift voor een low vision hulpmiddel werd ingediend. Personen die low vision hulpmiddelen ontvingen, waren voornamelijk vrouw, 60 jaar of ouder, niet (meer) werkzaam en hadden een aandoening van de gele vlek (maculadegeneratie) of oogzenuw (glaucoom). Dit kan worden verklaard doordat deze twee aandoeningen tot de meest voorkomende oogziekten bij mensen boven de 50 behoren, en door de hogere levensverwachting van vrouwen, waardoor zij in absolute aantallen vaker slechtziend worden. Vergrotingsloepen en schermlezers werden het vaakst vergoed. Hoewel we geen significante trends vonden in de kenmerken van personen die een low vision hulpmiddel hadden ontvangen, leek het aantal voorgeschreven low vision hulpmiddelen laag, gezien het geschat aantal mensen met een visuele beperking in Keulen.

Conclusie

Met dit proefschrift kunnen we concluderen dat er verschillende belemmerende en bevorderende factoren zijn op individueel, interpersoonlijk, organisatorisch, maatschappelijk- en beleidsniveau die van invloed zijn op de verwijspaden naar LVS in hoge-inkomenslanden.

Voor Nederland zijn kwetsbare subgroepen vastgesteld die extra belemmeringen kunnen ervaren voor het ontvangen van multidisciplinaire LVS: patiënten die minder mondig zijn, een lage sociaaleconomische status hebben, ouder zijn, op het platteland wonen en verder weg wonen van een multidisciplinair LVS-centrum. De resultaten geven aan dat oogzorgprofessionals en beleidsmakers zich vooral moeten richten op juiste en tijdige informatievoorziening en blijvende aandacht moeten hebben voor LVS-verwijzing. Daarnaast zouden hulpmiddelen zoals PROMs (Patient Reported Outcome Measures, ofwel patiëntgerapporteerde uitkomstmaten), dus vragenlijsten die worden gebruikt

om onder andere de kwaliteit van leven van patiënten vanuit hun eigen perspectief te meten, klinische beslissingsondersteunende systemen, zoals bijvoorbeeld een signaleringssysteem in het elektronische patiëntendossier dat aangeeft dat een patiënt in aanmerking komt voor een verwijzing, en communicatiehulpmiddelen voor patiënten, zoals bijvoorbeeld een vragenlijst met voorbeeldvragen die patiënten kunnen stellen tijdens hun afspraak met hun oogarts, kunnen helpen bij het verbeteren van verwijspaden. Verder zouden oogzorgprofessionals en beleidsmakers extra aandacht moeten besteden aan patiënten met mentale klachten, deze patiënten verwijzen naar GGZ instellingen of multidisciplinaire LVS en interventies gericht op mentale gezondheid aanbieden. Tegelijkertijd lijken niet alle patiënten die in aanmerking komen voor multidisciplinaire LVS behoefte te hebben aan deze ondersteuning. De resultaten van dit proefschrift laten zien dat patiënten mogelijk minder LVS-behoeften hebben omdat ze soms nog onder behandeling zijn voor netvliesaandoeningen of een staaroperatie hebben ondergaan waardoor ze weer wat beter zijn gaan zien. Daarnaast biedt de moderne technologie ook nieuwe mogelijkheden voor mensen met een visuele beperking waardoor deze zich langer zonder extra ondersteuning kunnen redden. Onderzoek naar de rol van low vision optometristen, opticiens en algemene optometristen in de verwijspaden naar LVS zou in toekomstig onderzoek extra inzicht kunnen geven in de factoren die van invloed zijn op het ontvangen van LVS in Nederland. Voor Duitsland bieden onze bevindingen ook een startpunt voor het onderzoeken van de verstrekkingen van LVS in de toekomst.

Met deze inzichten heeft dit proefschrift bijgedragen aan een beter begrip van de huidige verwijzingsprocedures en de verstrekking van LVS in twee hoge-inkomenslanden. Met de gegeven adviezen kunnen oogzorgprofessionals en beleidsmakers eraan bijdragen dat mensen met LVS-behoeften de juiste zorg krijgen op het juiste moment en op de juiste plaats.

LIST OF ABBREVIATIONS

AIC	Akaike information criterion
AUC	Area under the curve
AGENS	Working Group for the Collection and Use of Secondary Data (*Arbeitsgruppe Erhebung und Nutzung von Sekundärdaten*)
AWBZ	Exceptional Medical Expenses Act (*Algemene Wet Bijzondere Ziektekosten*)
CI	Confidence interval
CoRe-Net	Cologne Research and Development Network
COREQ	Consolidated criteria for reporting qualitative research
DGEpi	German Society for Epidemiology (*Deutsche Gesellschaft für Epidemiologie*)
DGSMP	German Society for Social Medicine and Prevention (*Deutsche Gesellschaft für Sozialmedizin und Prävention*)
DRP	Diabetic retinopathy
DTC	Diagnosis-treatment combination
EBM	German Uniform Assessment Standard (*Einheitlicher Bewertungsmaßstab*)
EGDPR	European General Data Protection Regulation
FDA	US Food and Drug Administration
GEE	Generalized estimating equations
GP	General practitioner
HIA	Dutch Health Insurance Act
ICD-10	International Classification of Diseases, 10th revision
ICD-10-GM	International Classification of Diseases, 10th revision, German modification
IVIs	Intravitreal injections
LBZ	National Basic Registration for Hospital Care (*Landelijke Basisregistratie Ziekenhuiszorg*)
LVAs	Low vision aids
LVS	Low vision services
MAR	Missing at random
MCAR	Missing completely at random
METC	Medical Ethics Committee (*Medisch Ethische Toetsingscommissie*)
MLVS	Multidisciplinary low vision services
OCTs	Optical coherence tomography scans
OR	Odds ratio
PHI	Private Health Insurance
PROMs	Patient Reported Outcome Measures
ROC	Receiver Operating Characteristics
SD	Standard deviation
SES	Socioeconomic status
SHI	Statutory Health Insurance

VEGF	Vascular endothelial growth factor
VI	Visual impairment
VIP-Path	Visually Impaired Person Path
WHO	World Health Organization
WLZ	Long-term Care Act (*Wet Langdurige Zorg*)
WMO	Social Support Act (*Wet Maatschappelijke Ondersteuning*)

Note: Where applicable, the original Dutch or German term is provided in italics for reference.

LIST OF PUBLICATIONS

Stolwijk ML, van Nispen RMA, van der Ham AJ, Veenman E, van Rens GHMB. Barriers and facilitators in the referral pathways to low vision services from the perspective of patients and professionals: a qualitative study. *BMC Health Services Research*. 2023;23(1):64. doi:10.1186/s12913-022-09003-0

Stolwijk ML, van Nispen RMA, Verburg IWM, van Gerwen L, van de Brug T, van Rens GHMB. Trends in low vision service utilisation: a retrospective study based on general population healthcare claims. *Ophthalmic and Physiological Optics*. 2022;42(4):828–38. doi:10.1111/opo.12982

Stolwijk ML, van Nispen RMA, van der Pas SL, van Rens GHMB. Big data study using health insurance claims to predict multidisciplinary low vision service uptake. *Optometry and Vision Science*. 2024;101(6):290-297. doi:10.1097/OPX.0000000000002134

Stolwijk ML, van Nispen RMA, van der Pas SL, van Rens GHMB. A retrospective big data study using healthcare insurance claims to investigate the role of comorbidities in receiving low vision services. *Frontiers in Health Services*. 2024;4:1264838. doi: 10.3389/frhs.2024.1264838

Stolwijk ML, Meyer I, van der Pas SL, Twisk JWR, van Nispen RMA, van Rens GHMB. Low vision aids provision in an urban setting in Germany between 2014 and 2017: a regional population based study with healthcare claims data. *Graefe's Archive for Clinical and Experimental Ophthalmology*. 2024. doi: 10.1007/s00417-024-06541-7

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Chapter 3: Trends in low vision service utilization: a retrospective study based on general population healthcare claims.
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Chapter 4: Big data study using health insurance claims to predict multidisciplinary low vision service uptake.
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Chapter 5: A retrospective big data study using healthcare insurance claims to investigate the role of comorbidities in receiving low vision services.
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Chapter 6: Low vision aids provision in an urban setting in Germany between 2014 and 2017: a regional population based study with healthcare claims data.
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PhD Period: June 2019 – May 2023
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Copromotor: Prof.dr. Ruth M.A. van Nispen
Department: Amsterdam UMC location Vrije Universiteit Amsterdam, Ophthalmology, De Boelelaan 1117, Amsterdam, the Netherlands

Workshops and courses	Organizator	Year	ECTS
Research Integrity	VUmc Academie/ Epigeum	2019	2
Writing a Scientific Article	Taalcentrum VU	2020	3
Getting Started with SAS Programming	Coursera/SAS, online	2020	0.82
Doing More with SAS Programming	Coursera/SAS, online	2020	0.82
Getting the most from Big Data Sets: Where to find them and how to use them effectively on-demand conference	The Association for Research in Vision and Ophthalmology (ARVO)	2021	0.32
Presenting and Pitching research in English	Taalcentrum VU	2021	2
Regression techniques	EpidM	2021	4
SQL school	AGENS	2022	1

Research meetings	Organizator	Year	ECTS
Intervision meetings for PhD candidates	Amsterdam Public Health research institute	2019	0.5
Weekly department research meeting	Low Vision Research Group, Ophthalmology department, Amsterdam UMC	2019-2023	1.5
Monthly Journal Club with other PhD candidates	Ophthalmology department, Amsterdam UMC	2019-2023	1.5

Conferences/symposia	Organizator	Year	ECTS
Programmalijnen Expertise Visueel	Koninklijke Visio, Bartiméus, Robert Coppes Stichting	2019	0.21
Using big data for healthcare research	Amsterdam Public Health research institute	2019	0.07
Amsterdam Public Health annual meeting	Amsterdam Public Health research institute	2019	0.29
CaRe days	Netherlands School of Public Health and CaRe Research	2021	1
Amsterdam Public Health annual meeting	Amsterdam Public Health research institute	2022	0.29

Working visits	Year	ECTS
3-months working visit at PMV research group in Cologne, Germany	2022	6

Oral presentations	Year	ECTS
VIP-path studie - Verwijzing van oogarts naar visuele revalidatie, Vereniging voor Revalidatie bij Slechtzienden, Najaarssymposium, Online	2021	1
Trends in low vision service utilization: a retrospective study based on general population healthcare claims big data, CaRe days, Netherlands School of Public Health and CaRe Research, Eindhoven, the Netherlands	2022	1
VIP-path study - Barriers in the referral towards low vision services, European Society for Low Vision Research and Rehabilitation (ESLRR), Online	2022	2
Trends in kenmerken van patiënten verwezen naar visuele revalidatiezorg op basis van declaratiegegevens van zorgverzekeraars, Nederlands Oogheelkundig Gezelschap, Annual Meeting, Groningen, the Netherlands	2022	1

Poster presentations	Year	ECTS
Factors influencing the referral pathways to low vision rehabilitation services from the patient's and professional's perspective: an exploratory qualitative study, Dutch Ophthalmology PhD Students (DOPS) congress, Nijmegen, the Netherlands	2020	1
Characteristics and healthcare utilization among patients of low vision services: a retrospective population-based descriptive study with healthcare claims, Association for Research in Vision and Ophthalmology (ARVO), Annual meeting, online	2021	2
Barriers and facilitators in the referral pathway to low vision services: a qualitative study. The Association for Research in Vision and Ophthalmology (ARVO), Annual meeting, online	2022	2

Teaching/Student supervision	Year	ECTS
Tutor/mentor of Low Vision Research intern meeting/intervision	2020	0.18

Other academic activities	Year	ECTS
Low Vision Research websiteclub	2021-2023	2

Awards

ARVO Staff Travel Grant, ARVO 2021 Annual Meeting

The Members-in-Training Outstanding Poster Award for the Low Vision, ARVO 2021 Annual Meeting

Publications not included in this thesis

Veenman E, Roelofs AAJ, Stolwijk ML, Bootsma AM, van Nispen RMA. Experiences of people with dual sensory loss in various areas of life: A qualitative study. PLoS One. 2023;18(9):e0272890.

Stolwijk ML. Verwijzing van oogarts naar visuele revalidatiezorg. MaculaVisie (Maculavereniging), Maart 2023.

FINANCIAL SUPPORT

The studies included in this thesis were financially supported by Visio Foundation.

ACKNOWLEDGEMENTS - DANKWOORD

Dit proefschrift zou niet tot stand zijn gekomen zonder de steun, kennis en bijdrage van velen. Ik wil iedereen hiervoor van harte bedanken en een aantal mensen wil ik in het bijzonder noemen.

Allereerst wil ik mijn **promotoren** ontzettend bedanken. **Prof. dr. Ger van Rens** en **prof. dr. Ruth van Nispen**, lieve **Ger** en **Ruth**, jullie begeleiding en betrokkenheid, zowel inhoudelijk als op andere vlakken, waren voor mij heel erg waardevol en een grote houvast. Bedankt voor de kans om aan dit project te werken en voor het vertrouwen dat jullie in mij hadden. Door onze overleggen, jullie expertise en jullie waardevolle feedback heb ik enorm veel geleerd over het doen van gedegen onderzoek. Dankzij jullie heb ik de ruimte gekregen om te groeien als zelfstandig onderzoeker en als persoon. Ik bewonder jullie tomeloze inzet voor mensen met een visuele beperking en wat jullie hebben opgebouwd met Low Vision Research. Ik ben dankbaar dat ik daar onderdeel van mocht zijn.

Beste **Ger**, ik wil je heel erg bedanken voor je begeleiding en je betrokkenheid tijdens dit traject, zelfs na je emiraat. Zo had ik vaak binnen no-time antwoord op mijn vragen of feedback op mijn aangeleverde werk. En ook onze gesprekken zullen me altijd bijblijven, vaak verrijkt met een leuke anekdote of wijs verhaal over het leven. Jouw relativeringsvermogen, scherpe inzichten en ondersteunende, bemoedigende woorden hebben me enorm geholpen gedurende mijn hele onderzoek en hielpen me om zaken in perspectief te blijven zien. Heel veel dank daarvoor.

Lieve **Ruth**, als dagelijks begeleider en copromotor ben je vanaf het begin van mijn onderzoeksproject een onmisbare steun voor mij geweest. Dankjewel voor de gezellige en leerzame overleggen en dat ik altijd bij je terecht kon met mijn vragen. Je hebt mij steeds het vertrouwen gegeven dat het goed zou komen, zelfs op momenten dat ik twijfelde. Ik waardeer je natuurlijke en respectvolle manier van begeleiden en de ruimte die je gaf voor mijn eigen ideeën en groei. Bedankt dat je zo enthousiast reageerde op mijn idee om op werkbezoek naar Duitsland te gaan en me daarin hebt aangemoedigd. Ook wil je danken voor je support met mijn presentaties. Heel veel dank voor alles.

Mijn grote dank gaat ook uit naar alle **deelnemers aan mijn onderzoek**. Jullie bijdrage aan de interviewstudie was van onschatbare waarde voor het succes van dit project. Bedankt voor jullie tijd, openheid en het delen van jullie ervaringen. Deze inzichten hebben niet alleen dit onderzoek verrijkt, maar hebben ook direct bijgedragen aan de aanbevelingen in dit proefschrift.

Ook wil ik **Vektis**, met name **Michiel**, **Ilona** en **Lieke**, en **Zorgverzekeraars Nederland** hartelijk bedanken voor het beschikbaar stellen van de dataset en voor het delen van hun kennis en expertise op het gebied van de Nederlandse declaratiegegevens.

Vielen Dank auch an die **Krankenkassen AOK Rheinland/Hamburg, BARMER Ersatzkasse, DAK-Gesundheit** und **Pronova Betriebskrankenkasse** sowie an das **CoRe-Net** für die Bereitstellung der Daten für die Deutsche Hilfsmittel Studie.

Mijn hartelijke dank gaat ook uit naar de leden van de **promotiecommissie**, **prof. dr. N. Schrage, prof. dr. J.R. Vingerling, dr. M. van Hecke, prof. dr. S.M. Imhof, prof. dr. H. Tan,** voor de tijd en moeite voor het kritisch lezen en beoordelen van mijn proefschrift en het deelnemen aan de oppositie.
Mein besonderer Dank gilt auch den Mitgliedern der **Promotionskommission, Prof. Dr. N. Schrage, Prof. Dr. J.R. Vingerling, Dr. M. van Hecke, Prof. Dr. S.M. Imhof** und **Prof. Dr. H. Tan**, für die Zeit und Mühe, die Sie in das sorgfältige Lesen und Bewerten meiner Dissertation investiert haben, sowie für Ihre Teilnahme an der Disputation.

Mijn lieve paranimfen, **Louise** en **Petra**, bedankt voor jullie vriendschap en steun. Zo fijn dat jullie mijn paranimfen willen zijn en dat jullie tijdens de verdediging naast mij staan.
Liebe **Louise**, seit unserem Psychologie-Master haben wir uns nicht nur bei all unseren Karriereschritten begleitet, sondern auch schon viele gemeinsame Abenteuer erlebt. Ob Wakeboarding, Reiten, Wandern, Tanzen, Wochenendtrips nach Warschau oder Paris, High Tea, gemeinsames Kochen oder Essen gehen– mit dir macht alles Spaß. Unsere Treffen und Telefonate waren immer eine willkommene Ablenkung während meiner Promotionszeit, und ich danke dir für deine Unterstützung und dein offenes Ohr. Vielen Dank, dass es dich gibt. Auf noch viele gemeinsame Jahre und schöne Momente zusammen.
Lieve **Petra**, iets meer dan een jaar geleden was ik jouw paranimf, en ik vind het heel fijn dat je nu de mijne wilt zijn. Het is bijzonder om dit moment samen te kunnen delen. Je bent naast een fijne collega ook een lieve vriendin. Bedankt voor je gezelligheid en betrokkenheid, zowel tijdens mijn PhD als daarbuiten. De treinreisjes naar Utrecht en loopjes van en naar kantoor waren altijd een mooie gelegenheid om bij te praten, en het is fijn dat we, ondanks dat je nu in Oostenrijk woont, nog steeds contact hebben. Het is leuk om te horen hoe goed jullie het daar hebben, en ik kom zeker nog een keer langs. Ik kijk uit naar nog veel meer gezellige momenten en andere mooie herinneringen samen.

Daarnaast wil ik ook graag alle **co-auteurs** bedanken voor hun waardevolle bijdrage aan de artikelen van dit proefschrift: **Stéphanie L. van der Pas, Jos W.R. Twisk, Tim van de Brug, Lia A. J. van der Ham, Esther Veenman, Ilona W.M. Verburg** en **Lieke van Gerwen**.

Beste **Stéphanie, Jos** en **Tim**, bedankt voor jullie waardevolle hulp bij de statistiek en voor de fijne samenwerking. Lieve **Stéphanie**, jou wil ik in het bijzonder bedanken. Ik ken niemand die complexe statistiek zo helder kan uitleggen als jij. Ik heb veel van je geleerd. Vooral hoe je uit meerdere beschikbare methoden een goed onderbouwde keuze maakt, en over de statistische uitdagingen bij het werken met grote datasets. Mede dankzij jouw expertise en inzet zijn drie mooie artikelen tot stand gekomen op basis van Nederlandse en Duitse declaratiegegevens. Lieve **Lia**, dank je wel voor het delen van je uitgebreide kennis over kwalitatief onderzoek en voor de fijne samenwerking. Dankzij jouw input is het artikel over de interviewstudie naar een hoger niveau getild. Lieve **Esther**, bedankt voor de fijne samenwerking aan onze beide interviewstudies. Dank voor je kritische blik en het fijne sparren. Ik ben trots op de resultaten die we samen hebben behaald. Lieve **Ilona** en **Lieke**, bedankt voor jullie waardevolle bijdragen en kennis op gebied van de declaratiegegevens en jullie feedback op het artikel over de trends in LVS gebruik.

Lieve **(oud-)collega-onderzoekers** van **Low Vision Research** en **Oogheelkunde**: **Aleid, Annabel, Arthur, Buket, Edine, Ellen, Esther, Hilde, Katie, Laura, Leo, Lia, Jenny, Lorenzo, Manon, Maria, Mariska, Mieke, Milo, Petra, Richard, Rob, Vera, Wouter, Yasmin** en **Yvonne**. Ik wil jullie allemaal bedanken voor de fijne tijd die ik de afgelopen vijf jaar heb gehad. Door onderdeel uit te maken van de diverse onderzoeksgroep van Low Vision Research, met zoveel verschillende achtergronden en onderzoeken, heb ik veel van jullie kunnen leren. Dank ook voor de gezelligheid tijdens de lunches, researchmeetings, APH-meetings, DOPS, ARVO, borrels, verdedigingen en de digitale momenten achter onze computers tijdens de COVID-periode. Ik hoop dat ik velen van jullie blijf zien en spreken.
Lieve **Petra** en **Manon**, het was heel fijn om jullie als kamergenootjes te hebben en samen te sparren over PhD-dingen en veel andere onderwerpen. Bedankt voor de gezelligheid en de steun in drukke tijden. Lieve **Manon**, we zijn rond dezelfde tijd begonnen met onze PhD, en daardoor konden we veel delen, zowel de mooie momenten als de uitdagingen. Dat vond ik heel waardevol. Bedankt voor alle gezellige koffiemomenten en gesprekken. Lieve **Esther**, naast een fijne co-auteur, ben je ook een hele fijne collega. Met plezier kijk ik terug op onze gezellige bijpraatmomentjes. Dankjewel ook voor je betrokkenheid. Lieve **Yasmin**, bedankt voor de gezelligheid tijdens de terugreizen van kantoor naar Utrecht en de fijne gesprekken die we hebben gehad, zowel over werk als over veel andere dingen. Dank ook voor je vriendschap, betrokkenheid en steun tijdens de PhD en daarbuiten. Lieve **Katie**, het was heel leuk om samen met jou en Yasmin de Singelloop te lopen. Bedankt ook voor alle gezellige gesprekken op kantoor en je betrokkenheid.

Liebe **PMV-Forschungsgruppe**: **Ingo, Peter, Ingrid G., Ingrid S., Jutta, Birgit, Veronika, Adriana, Katrin, Heike, Katja** und **Charlotte**, vielen Dank für das herzliche Willkommen bei euch in Köln und die tolle gemeinsame Zeit, an die ich noch immer gerne zurückdenke.

Ich möchte mich auch herzlich für das Teilen eures Wissens und eurer Expertise bezüglich der GKV-Routinedaten bedanken – davon konnte ich viel lernen. **Ingo**, vielen Dank, dass du mir die Möglichkeit gegeben hast, als Gastwissenschaftlerin bei euch am LVS-Projekt auf Basis der Routinedaten zu arbeiten, und für die großartige Zusammenarbeit. Schade, dass es mit der Stelle bei euch nicht geklappt hat, aber wer weiß, vielleicht ergibt sich in der Zukunft ja noch eine Zusammenarbeit – ich würde mich freuen. **Peter**, vielen Dank für deine Unterstützung bei SQL und REX. **Ingrid G.**, vielen Dank für deine wertvolle Hilfe bei der Plausibilitätsprüfung der Hilfsmitteldaten. **Jutta, Veronika, Adriana, Heike** und **Katrin**, danke, dass ihr bei all meinen Fragen so hilfsbereit wart.

Lieve **Maxim**, bedankt voor je hulp bij het in kaart brengen van de afstanden tot de expertisecentra met behulp van Google Maps. Wat een flinke klus om voor maar liefst 4000 postcodes de afstanden nauwkeurig vast te leggen. Jouw zorgvuldigheid en doorzettingsvermogen hebben dit mogelijk gemaakt.

Lieve **Assia**, bedankt voor je ondersteuning met het transcriberen van de interviews voor de interviewstudie. Mede dankzij jouw inzet hadden we een solide basis voor de data-analyse.

Beste **Esther Scheide**, hartelijk bedankt voor het prachtige ontwerp van de cover en de zorgvuldige afwerking van het binnenwerk. Jouw creativiteit en oog voor detail hebben mijn proefschrift een professionele en mooie uitstraling gegeven.

Dan wil ik nu graag mijn lieve **vrienden** en **familie** bedanken. Jullie verdienen een bijzondere vermelding in dit proefschrift, want met jullie is het leven niet alleen een stuk leuker, maar jullie brachten ook fijne afleiding, steun en gezelligheid tijdens mijn gehele promotietraject. Nun möchte ich gerne meinen lieben **Freunden** und meiner **Familie** danken. Ihr verdient eine besondere Erwähnung in dieser Dissertation, denn mit euch ist das Leben nicht nur viel schöner, sondern ihr habt auch während meiner gesamten Promotionszeit für willkommene Ablenkung, Unterstützung und gesellige Momente gesorgt.

Liebe **Lotti, Pia, Lara, Greta, Juliane** und **Emily** – meine Münsteraner Freundinnen, es ist so schön, dass wir uns nach all der Zeit und den unterschiedlichen Wohnorten in allen Himmelsrichtungen immer noch so regelmäßig hören und sehen. Ich weiß es wirklich zu schätzen, euch an meiner Seite zu haben. Danke, für eure Freundschaft, für die schönen gemeinsamen Momente und für eure Unterstützung. Liebe **Lotti** und **Pia**, ihr Kleenen, euch möchte ich besonders danken für eure Ermutigung, die Promotion anzugehen, für eure Unterstützung, und dafür, dass ich immer bei euch anklopfen durfte. Ihr hattet immer wertvolle Ratschläge oder wart eine schöne Ablenkung in turbulenten Zeiten. Danke, dass ihr für mich da seid.

Liebe **Lena** und **Paul**, es war so schön, euch während meines Aufenthalts in Köln in derselben Start zu wissen. Ihr und unsere spontanen Treffen haben meine Zeit unglaublich bereichert. Liebe **Lena**, danke für die schönen gemeinsamen Momente, deine guten Ratschläge, deine Unterstützung und deine Freundschaft. Ich freue mich schon auf unser nächstes Sommerrollen-Essen.

Lieve **Rens,** wat is het fijn om jou als vriendin te hebben. Dank je wel voor je betrokkenheid, concertbezoekjes, koffiemomentjes, borrels, wandelingen, dansjes – en je goede adviezen. Super fijn dat je in de buurt woont, en altijd een steun en gezellige metgezel voor me bent.

Liebe **Sarah** und **Thorsten,** vielen Dank für die schönen gemeinsamen Frühstücke und das Waffelessen. Euer stetiges Interesse an meiner Dissertation bedeuten mir viel – danke für eure Freundschaft. Da sage ich nur: Yippie, Yippie, Yeah. Liebe **Sarah**, danke für die Telefonate, die Ermutigungen, dein offenes Ohr, die Besuche auf dem Weihnachtsmarkt und das Wochenende in Ameland – sie waren eine wunderbare Ablenkung. Schön, dass es dich gibt.

Lieve Eva, het is fijn dat ik op jou als vriendin kan rekenen en je dichtbij woont. Dank je wel voor je steun, je luisterend oor en alle gezellige wandelingen, theetjes, borrels en etentjes samen.

Liebe **Hannah** und **Mareike**, es ist schön, dass wir trotz der Entfernung – zwischen Australien, Deutschland und den Niederlanden – länderübergreifend in Kontakt bleiben. Danke für euer Interesse, eure Unterstützung und eure Freundschaft.

Lieve **Daantje**, het is altijd fijn als we elkaar zien en spreken. Dank je voor alle gezellige wandelingen, bijpraatmomentjes, je vriendschap en je steun.

Liebe **Doppelkopf-Mädels**, **Josi, Lisa** und **Louise**, unsere Doppelkopf-Treffen – ob online oder in Person – waren immer eine schöne Ablenkung, begleitet von Wein, köstlichem Essen und Lebensupdates. Vielen Dank.

Lieve **ooms** en **tantes,** hartelijk dank voor het warme welkom in Nederland en voor jullie steun en interesse. Een paar van jullie wil ik in het bijzonder noemen.
Lieve **Petra** en **Henny** (in memoriam), bedankt voor de gezellige lunches en koffiemomenten, en voor jullie betrokkenheid en adviezen, dat waardeer ik enorm. Wat jammer dat jij, Henny, er niet bij kunt zijn tijdens mijn verdediging, maar in gedachten ben je er zeker aanwezig.
Lieve **Lydia** en **René,** ik zal nooit vergeten hoe we met jullie busje onze groene bank door de smalste straatjes van Utrecht hebben weten te krijgen. En **Lydia**, super leuk dat we tijdelijk collega's waren bij Amsterdam UMC — gezellig dat we af en toe samen koffie konden drinken. En bedankt ook voor de fijne bijpraatmomentjes en adviezen.

Lieve **Guus** en **Trui**, het is altijd leuk om met jullie over al het wel en wee van de wereld te hebben, samen te eten en foto's te bekijken van jullie indrukwekkende reizen. Bedankt voor jullie steun, interesse en betrokkenheid.

Lieve **Tonnie, Ria, Dirk, Emma, Joep** en **Olle**, ik ben dankbaar dat ik de meest bijzondere momenten van het jaar samen met jullie mag doorbrengen, vaak met iets te veel Chinees eten dan we eigenlijk aankunnen. Dank voor jullie steun, jullie interesse en vooral voor jullie gezelligheid de afgelopen jaren.

Liebe **Judith,** lieber **Matthias,** lieber **Bas,** liebe **Jana,** lieber **Henri** und liebe **Emma**, vielen Dank für euer Interesse und eure Unterstützung. Es ist immer so schön, wenn wir uns sehen und hören. Diese gemeinsamen Momente bedeuten mir sehr viel. Liebe **Judith** und lieber **Bas**, meine große Schwester und mein großer Bruder, ich bin super stolz auf euch und hab euch lieb.

Lieve **Mama** en **Papa**, bedankt voor jullie onvoorwaardelijke liefde en steun. Jullie hebben me altijd de ruimte gegeven om mijn eigen pad te kiezen, waarvoor ik jullie heel erg dankbaar ben. Ik hou van jullie. Lieve **Mama**, ik ben heel trots op je. Hoe je moeilijke tijden hebt doorstaan en hoe je met veel doorzettingsvermogen het leven opnieuw hebt vormgegeven, vind ik ontzettend knap. Bedankt voor je betrokkenheid en je steun in alles wat ik doe. Ik gun je het allerbeste en hou van je. Lieve **Papa,** wat is het jammer dat je dit hele promotieavontuur niet meer hebt kunnen meemaken. Wat had ik dit graag met jou willen delen. Gelukkig heb ik nog een paar van je oude mails bewaard, met jouw steunende woorden die me door moeilijke momenten hebben geholpen. Ik vind het een bijzonder idee dat jij destijds ook in Amsterdam bent gepromoveerd. Dat maakt dit moment voor mij extra speciaal. In gedachten ben je erbij op 14 februari.

Lieve **Thomas**, mijn beste vriend en lieve partner. Ik prijs me gelukkig dat ik jou heb ontmoet en dat we al bijna 10 jaar samen door het leven gaan. Bedankt voor je liefde, geduld en voortdurende steun. Zonder jouw vertrouwen in mij, jouw relativeringsvermogen, rust, analytische blik, peptalks, knuffels, luisterend oor en grapjes gedurende het hele promotieavontuur was het mij nooit gelukt om dit proefschrift af te maken. Bedankt dat je er altijd bent. Ik hou van jou en ik kijk uit naar de toekomst die we samen gaan bouwen.

Mijn lieve **Evie**, jouw komst was een extra motivatie voor mij om mijn proefschrift af te maken. Ik wilde namelijk alle focus en ruimte voor jou hebben zodra je er zou zijn. En alsof je voelde dat alle grote deadlines eindelijk achter de rug waren, besloot je drie dagen nadat ik mijn proefschrift had ingeleverd, je intrede in de wereld te doen. Sindsdien verras je me elke dag. Het is zo bijzonder om je te zien groeien en je persoonlijkheid te ontdekken. En

jouw lach en knuffels zijn het mooiste wat er is. Wat zijn wij ongelofelijk blij met jou en wat ben ik trots dat ik jouw moeder mag zijn. Ik wens je het allerbeste toe in je leven en zal er alles aan doen om je het vertrouwen en de veiligheid mee te geven die je nodig hebt om je eigen pad te vinden. Ik hou van je.

CURRICULUM VITAE

Miriam L. Stolwijk was born on June 28th, 1991 in Münster, Germany as the daughter of her Dutch parents Nicolaas and Petra. Along with her sister Judith and her brother Sebastian she grew up in the village of Altenberge near Münster. After completing secondary school in Germany in 2010 (Abitur at the Gymnasium Marienschule Münster), she started her bachelor's study psychology at Twente University in Enschede, the Netherlands.

After obtaining her bachelor's degree in 2013, she worked as an activity coordinator at a nursing home. In 2014, she started her master's study clinical and health psychology at Utrecht University, which she completed in 2016. Her master's studies included a research internship at ARQ National Psychotrauma Centre, focusing on individual and family characteristics and the course of treatment of the post-war generation. Additionally, she completed a clinical internship at an outpatient clinic for patients with medically unexplained somatic symptoms.

From 2017 to 2019, Miriam worked as a project officer and researcher at a labor market fund for social services (FCB), where she managed and provided support for multiple (research) projects. Additionally, from 2018 to 2019, she worked as a research assistant at the research group Innovative Social Services at the HU University of Applied Sciences Utrecht.

In 2019 she started her PhD research at Low Vision Research at the Department of Ophthalmology at the VU University Medical Centre in Amsterdam. Her PhD research is subject of this thesis. It was conducted under supervision of prof. dr. Ger H.M.B. and prof. dr. Ruth M.A. van Nispen. During her PhD, she visited the PMV research group at the medical faculty of the University of Cologne, Germany, which focuses on healthcare and health services research based on German healthcare claims. During this collaboration, she conducted a study on LVS provision in Cologne, which is included in this thesis (Chapter 6).