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**REVIEW**

# Promoting and protecting mental health of people living with adventitious blindness and low vision: A scoping review of protective and risk factors

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**ABSTRACT**

**Introduction:** People living with visual impairment (VI) have a higher prevalence of mental health challenges versus those without VI. The occurrence of clinical depression has been estimated at 10% to 40% among this population. Specifically, adults of working age (18-65 years) living with adventitious VI have a higher risk of severe psychological distress, disruption of employment status and attendant loss of income. Hence, our overall research question was: What is known from existing literature about the protective and risk factors for mental health of working age adults (18-65 years) with adventitious total bilateral blindness and low vision?

**Methods:** Using Joanna Briggs Institute guidance, articles in English were systematically searched across six databases: MEDLINE, PsycINFO, CINAHL, EMBASE, PsycArticles, Web of Science. Searches were also conducted in various websites such as: World Blind Union, World Vision, African Union, and Royal National Institute of Blind People. Two reviewers independently screened titles and abstracts. Full texts were then reviewed by the team. Of 4,352 identified titles, 92 were included. We thematically analysed the evidence using inductive and deductive approaches with the latter informed by Dahlgren and Whitehead's socioecological model.

**Results:** Thirteen (13) risk and 10 protective themes were identified. Rehabilitation (protective) was the commonest theme in 30.4% of studies, followed by negative social support (risk) at 17.4%. Most research was conducted in the US (43.5%). Critical findings included: strong socially determined nature of mental health; coexistence of positive and negative social support and limited studies of lived experience. Our analysis also revealed layers of under and mis-representation; these included scarce research from low- and middle-income countries (LMICs), non-uniformity in definitions of blindness and incomplete reporting of participant characteristics.

**Conclusion:** This is the first scoping review to comprehensively explore protective and risk factors for mental health for people living with adventitious total bilateral blindness and low vision. This study reports multiple upstream drivers acting singularly and in concert to exert a profound determining influence on the mental health of our target population. It also highlights the institutional ways that the condition and related issues are reported, recorded and researched.

**Keywords:** Acquired blindness, low vision, mental well-being, partial sight, protective factors, risk factors

**Abstract in Español at the end of the article**

## INTRODUCTION

The human brain acquires 80% of information (learning, activities, perception, and cognition) from the sense of vision [1,2]. Hence, people who acquire visual impairment (VI), experience profound consequences in nearly every part of their lives: personal care, mobility, employment, education, recreation, and socialization [3]. They also have a significantly higher prevalence of mental health problems such as post-traumatic stress disorder and depression than those without VI [4–8]. Specifically, Grigo et al, estimated clinical depression to be at 10% to 40% among people living with VI [9]. However, with proper and adequate support, many people living with VI are able to adapt, live independently, be productive and have improved quality of life [10,11]. Nevertheless, the literature review presented here is necessary to understand the profound loss and attendant mental health challenges experienced by people who have acquired the condition of VI. It is about promoting awareness regarding the challenges they face while also advocating inclusion for this study's target population.

The target population are 'people living with VI', which is a general term used in describing an array of visual function ranging from low vision to total blindness [12,13]. The criteria utilized in the definition of blindness and low vision varies [14]. Low vision is loss of vision which cannot be improved with eyeglasses, contact lenses, medical or surgical procedures [15,16], while total blindness is the total absence of light and form perception or the total absence of sight [17,18]. However, in the International Classification of Diseases (11th revision) (ICD), blindness is classified differently [19]. In ICD-11, the term blindness includes people living with residual vision alongside people living with total blindness [19]. This review adopted the former definition of total blindness [17,18] as the authors considered it to be more explicit.

Visual impairment can be categorized according to age at onset: adventitious or congenital [12,20]. Adventitious VI occurs when an individual loses vision at or above the age of five while congenital VI is vision loss which occurs before the age of five [12,20]. Without retention of any useful visual imagery or memory [21], people living with congenital VI cope with loss of vision through tactile-auditory (touch/hearing) mechanisms as well as verbal descriptions from other people [20]. These processes provide the basis for conceptual development in people living with congenital VI [12,20]. On the other hand, people living with adventitious VI can form a visual idea of an object based on their former visual experiences [20]. However, they often have to cope with loss of their vision and need to make significant changes such as relearning skills to carry out daily living tasks [12,20]. Additionally, they are more severely impacted by the level of negative consequences of VI and more predisposed to lower psychological well-being and resilience [22,23].

The age group for this review was working age adults defined here as individuals 18-65 years of age [24], living with adventitious VI. We chose to focus on this population because loss of vision in working age adults occurs during the years when they are expected to have the most economic productivity [25]. For people who acquired VI during working age, employment status is often disrupted [26], resulting in loss of income, increased poverty and levels of hunger, as well as poor standards of living [27]. This can limit affordability and accessibility of health care services [27]. Another consideration is that working age adults have a greater risk of severe psychological distress than older adults [28]. Hence it is important to improve understandings of how to protect and promote the mental health of working age adults (18-65 years) living with adventitious VI [29].

Despite being more predisposed to mental health challenges [4–6,22], no review to date has comprehensively explored the determinants of protective and risk factors for mental health in this target population. Research into the determinants of mental health in this population has for the most part remained fragmented and does not provide a holistic view of these factors. Some authors, such as Senra et al, have systematically reviewed the psychological adjustment of adults to adventitious VI [30]. This refers to exploring the mechanism by which a person elicits psychologic abilities and behaviours to realistically adapt to changes and limitations that VI imposes [30,31]; in other words, investigation of

factors that influence emotional adaptation to VI.

Note that a person living with VI may be well adjusted to VI but may also be a victim of social exclusion or abuse, which can be detrimental to his/her mental health. Hence, adjustment to VI is not a guarantee that the person is immune to mental health issues. Although Senra et al's focus is on adventitious VI, our aims are different. It is well-established in the evidence base and in this study that adventitious VI significantly affects the psychological wellbeing of this population [32,33]. Our study's focus transcends that of the above study (impact of VI) and instead seeks to review factors which protect or are detrimental to the mental health of this population [29]. Therefore, our study aim is more holistic and wider in scope.

An additional consideration is that Senra et al's study was undertaken over a decade ago and since then there has been lack of research in this area, which further justifies the need for this scoping review to fill the literature gap [29]. Hence, this is the first study to systematically explore the protective and risk factors for mental health in this target population [29]. Exploring these determinants is critical for the prevention and management of mental health challenges in our target population.

Protective factors are factors that fortify an individual's mental health and act to improve one's capacity to cope with situations that are challenging [34]. These factors also decrease the negative effect of risk factors on the outcomes of a problem [35]. For example, multiple studies have reported factors which positively impact mental health (protective) of people living with VI, such as multidisciplinary rehabilitation [36] and social support [9,37].

Conversely risk factors have an adverse effect, predisposing individuals to worsening mental health outcomes [34]. Some risk factors for mental health of people living with VI, reported by other authors, include poor socioeconomic status [38,39] and discrimination [40]. Taken together, knowledge of various factors that impact on mental health is important to inform the design of appropriate mental health programmes for the target population, and boost mental health literacy [29].

The specific objective of this review was to explore factors impacting on the mental health of our target population through a review of available literature. Therefore, the overall research question was: What is known from existing literature about the protective and risk factors for mental health among working age adults (18-65 years) with adventitious total bilateral blindness and low vision? Sub questions were:

(1) What are the protective factors for mental health among working age adults living with adventitious total bilateral blindness and low vision?

(2) What are the risk factors for mental health problems among working age adults living with adventitious total bilateral blindness and low vision?

(3) What are the evidence gaps related to mental health among working age adults living with adventitious total bilateral blindness and low vision?

# METHODS

Scoping reviews are aimed at systematically identifying and charting the scope of available evidence on a specific subject matter or area [41]. Scoping reviews collate and describe the evidence which is summarized and presented in a demonstrable format for illustration [42]. Therefore, scoping reviews can be used to form a research agenda, for the advancement of the field and identification of areas requiring future systematic reviews or other kinds of evidence synthesis, and for the identification and analysis of knowledge gaps [43,44]. According to Peters et al, when authors are interested in identifying specific concepts in the evidence base and to map, report or discuss these concepts, a scoping review is the preferred choice [45]. The reason is that they are aimed at providing an overview or map of the evidence [44,45]. More so, scoping reviews are particularly of use when a research area is yet to be comprehensively reviewed [46]. These characteristics make scoping review ideal for achieving the research objective and answering the research questions.

The conduct of our scoping review was underpinned by the latest Joanna Briggs Institute (JBI) guidance [42,43] and the PRISMA-ScR (*Table S1, Supplementary material*) reporting guidelines [47]. The JBI guidance provides a methodology used to conduct scoping reviews to ensure rigour, transparency and trustworthiness of the process [45,48] while the PRISMA-ScR is a complementary checklist that provides guidance on how to report the scoping review [47,49]. The PRISMA-ScR is used in tandem with the JBI guidance to guarantee consistent reporting [41,43,44]. Due to the complementary nature of the JBI guidance and the PRISMA-ScR checklist, no conflicts arose with their use. In line with these guidelines, an a priori protocol for this review was developed [43] and registered in Open Science Framework on June 23, 2023 [50]. The protocol was then published in PLOS One Journal on the 10th of January, 2024 [29].

In addition to the JBI guidance and PRISMA-ScR, this study applied a socioecological framework, considering the association between VI and socioeconomic disadvantage [51–56]. A study which used data from 190 territories and countries, found a close strong, negative correlation between VI burden and national socioeconomic indicators [57]. Moreso, a large number of people living with VI (90%) reside in low- and middle-income countries (LMICs) [58] Furthermore, cultural differences may influence coping mechanisms and mental health outcomes in people living with VI [40]. Research involving minority ethnic communities in the UK reported that Asian participants living with VI had poorer mental health than Black participants [40]. However, both Asian and Black participants compared to White participants had reduced likelihood of receiving the amount

of emotional support they required to move on with their lives [40]. The nature and population burden of VI locates it as an issue of social justice, hence the application of the model. The Dahlgren and Whitehead's socioecological model conceptualises determinants of the population's health as conditions they live and work in, support networks and wider socioeconomic, environmental and cultural contexts (Figure 1) [59–61].

## Search strategy

We conducted literature searches in MEDLINE, PsycINFO, CINAHL, EMBASE, PsycArticles, and Web of Science databases [29,42,43]. The research questions were broken down into composite search terms (made of synonyms) and search term combinations were subsequently applied to bibliographic sources. To ensure a comprehensive literature search, we employed a three-step search strategy informed by JBI guidance [43]. The first step comprised a preliminary limited search undertaken in CINAHL, MEDLINE, PsycArticles and EMBASE on the 28th of March 2023 for identification of articles [29]. The team collaborated with a librarian in conducting this first step.

The initial strategy was refined by repeatedly analysing text words (retrieved from titles and abstracts of articles) and index terms. The full search strategy conducted in the MEDLINE database is provided (*Table S2, Supplementary material*) [29,42,43]. The second step involved searching all databases (MEDLINE, PsycINFO, EMBASE, Web of Science, CINAHL, and PsycArticles) using every keyword and index term found. We included MEDLINE as some time had elapsed between the first and second step.

Due to the uniqueness of the databases, searches were adapted to suit each database. An example of the search conducted in MEDLINE included using one of the Boolean phrases 'OR' to combine key words such as: exp Blindness/ OR Blindness.tw. OR (visual$ adj1 impair$).tw. OR (vision adj1 impair$).tw. OR (vision adj1 loss).tw. OR (loss adj3 vision).tw. OR (low adj1 vision).tw. OR (partial$ adj1 sight$).tw. This second step was conducted from 23rd to 24th of June 2023. Given the comprehensiveness of the full search strategy, no more modifications were made in June. However, one additional article was retrieved in MEDLINE due to the time lapse between the date of the initial search and the final search. In the third step, reference lists of all eligible studies were searched for additional relevant studies [42,43].

To conduct hand searching [62], the authors searched Google for names of journals and websites that had the terms: VI, blind(ness), vision; or those that published articles on VI. It was assumed by the authors that such journals or websites were likely to contain relevant articles. These target journals included: Journal of Visual Impairment and Blindness (JVIB) (from 1907 to 2024) and Visual Impairment Research (VIR) (from 1999 to 2009), while the key websites of practitioner and advocacy groups included: World Blind Union, World Vision, African Union, and Royal National Institute of Blind People. The VIR journal title ceased in 2009, hence the reason the hand searching stopped at 2009.

We also conducted author searching by compiling names of key authors of relevant articles and searched for other articles written by these authors in relation to the review's objectives [62]. Key word and Table of Contents (TOC) email alerts were set up on the 22nd of June and 11th of July 2023 in American Foundation for the Blind, Google, Google Scholar and 15 key journals including British Journal of Ophthalmology, American Journal of Ophthalmology and Archives of Public Health [29]. The authors obtained ideas of some journals for TOC and email alerts by searching for publishers of included studies.

## Inclusion criteria

Studies were included if they reported on factors which impacted positively and/or negatively on mental health of working age adults living with adventitious VI as defined by the included studies [29]. According to WHO, mental health refers to the state of mental well-being that allows individuals to cope with life stresses, recognise their capabilities, work and learn well, and contribute to their community [63]. We acknowledge that mental health is a broad term. Hence, we included studies that reported any mental health outcome in line with the way mental health was defined in the included studies.

We included articles of participants living with both congenital and adventitious VI only if the participants living with adventitious VI were at least 50% of the total sample size given that this research focus is an under-researched area where there are very limited number of studies. Hence, we included mixed population of adventitious and congenital VI where at least 50% of the population had adventitious VI in order to obtain a substantial number of the target group of interest, as well as have broader inclusion criteria to address the paucity of the evidence base for our target population. More so, the authors sought to avert excluding potentially important data about people living with adventitious VI.

Furthermore, our study population's age range was 18-65 years, but studies were eligible if they included participants that spanned this age range, as the authors did not want to exclude potentially useful data based on an article not fitting 'neatly' into the exact inclusion criteria of age 18-65 years. After careful considerations, all the included articles that spanned the age range of this study were deemed by the authors to contain useful data regarding the target population, hence to exclude them was considered illogical. To ensure comprehensive results, neither geographic location nor date limits were imposed. Quantitative, qualitative, and mixed methods study designs and research published in English language were eligible [43]. Also, studies were excluded if they were commentaries, editorials, letters, conference

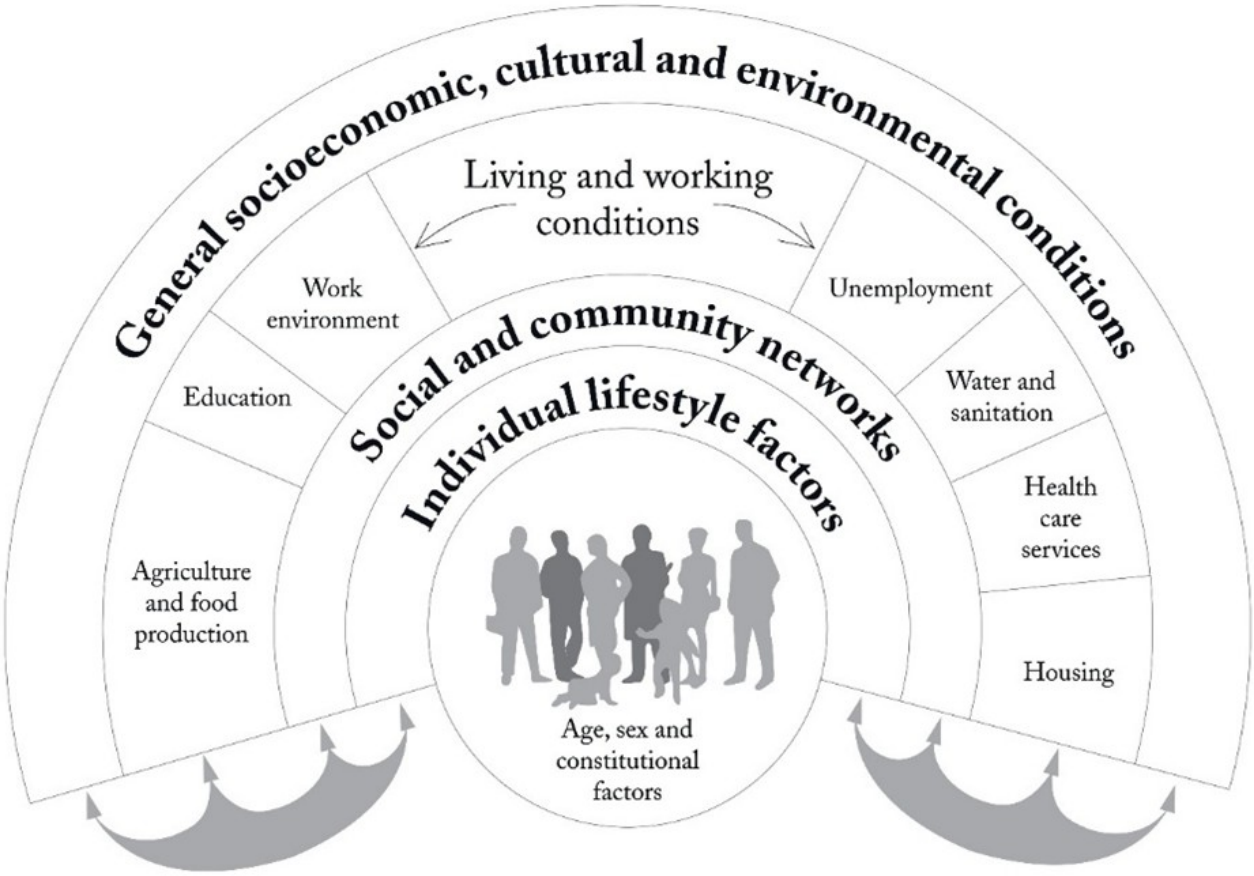


**Figure 1.** Dahlgren and Whitehead's socioecological model [59–61].

abstracts, text, and opinion papers [43].

### Study screening and selection

We conducted deduplication and subsequent screening in Rayyan [64]. Two reviewers (ND and MA) independently conducted double screening (100% each) of titles and abstracts in Rayyan, while LD, HMM and ZCS screened a subset of 10% each [64]. The review team considered and resolved the discrepancies that arose. We uploaded full text pdf copies of eligible articles into Rayyan to enable us conduct full text screening [64]. One reviewer (ND) conducted 100% full text screening of eligible articles while MA, HMM, LD and ZCS screened a subset of the articles (15.6%, 8.2%, 2.2%, 2.2% respectively). The review team resolved the discrepancies that arose from the full text screening.

### Data extraction

Data extraction was conducted in Rayyan [64] using a template adapted from the JBI Evidence Synthesis manual [43]. The template was piloted at protocol stage by two reviewers using four different articles chosen randomly [43]. Piloting of the randomly selected articles served various purposes such as ensuring that the authors would not conduct an "empty review" (absence of eligible articles for inclusion) [65], refinement of the data extraction template and clarifications on other review processes [43]. The four piloted papers consisted of two qualitative, one quantitative and one mixed-method designs. However, some of the studies had missing data such as country of publication and defined age range. Only two of the piloted studies were among those included for this review [66,67].

Data items were extracted at study and participant level. Data were extracted on the main characteristics of each eligible study. These included: author(s) information, study year and location, aims, study methods, participant demographic data (sample size, age, gender, type of VI, onset of VI) and outcomes data (protective and risk factors for mental health). One reviewer (ND) conducted data extraction while four other reviewers (LD, HMM, ZCS and BE) revised and crosschecked the extracted data to ensure that there were no data extraction errors. We sent emails to authors of included articles to obtain additional or omitted information for the review [43].

Furthermore, scoping reviews are generally not designed to appraise or exclude studies based on their quality because they are inherently structured to give an overview of available literature irrespective of quality [42,46]. Unlike systematic reviews, scoping reviews are not focused on answering questions of effectiveness which would have necessitated quality assessment [68]. Based on these arguments, assessment of methodological quality was not conducted in this review as it would

have served no empirical purpose.

Inductive and deductive approaches were used during thematic analysis of the substantive content. The inductive approach involved themes and many subthemes which emerged from the data while the deductive entailed a priori themes [69] informed by Dahlgren and Whitehead's socioecological model such as social support (positive and negative), rehabilitation, education and employment [59–61]. Deductive and inductive analysis were conducted concurrently and iteratively while reviewing each included article. Themes and subthemes that emerged from the data were grouped under the corresponding layers of influence of the existing socioecological framework. Using thematic analysis, similar protective or risk factors were grouped into composite themes. Through this grouping, the team identified 23 themes in total that impacted on the mental health of people living with adventitious VI. The team considered 10 themes to be protective while 13 themes were risks. Each theme comprised different subthemes, and the themes were analysed ranging from the theme with the highest number of articles.

### Data presentation

We presented results in tabular and visual formats [43]. To explore the geographical distribution of the evidence base, a map was used to show the number of studies published in each country. We used Dahlgren and Whitehead's socioecological model to analyse our findings by mapping the protective and risk factors identified by the different levels of influence within the model [59–61]. Characteristics of included studies were presented in tables according to the data extraction template (*Table S3, Supplementary material*). Factors were considered protective if the studies reported that they improved mental health, and considered risk factors if they reportedly compromised or worsened mental health.

## RESULTS

From the six databases searched, we identified 4,352 studies as shown in the PRISMA Flow Diagram (Figure 2) [70]. Following deduplication, 3,988 title and abstracts were screened. After excluding 3,757 articles, 231 were considered eligible for full text screening. Fifteen (15) articles could not be retrieved due to unavailability. A further 141 articles were excluded, leaving 75 eligible for inclusion. Seventeen (17) additional articles were found through TOC alerts (2), hand searching of journals (2) and reference lists of included studies (13). Data were extracted and analysed from 92 articles in total.

### Study and sample characteristics

The number of published articles per country was as follows: US was the highest at 40 (43.5%); China: 6 (6.5%); UK and Australia each 5 (5.4%); Nigeria, Germany, Greece, Italy, India and Netherlands each 3 (3.3%); Brazil, Iran, Japan, Israel, and Canada each 2 (2.2%) while Ghana, Turkey, New Zealand, Jordan, South Korea, Poland, Thailand and Nepal had the least at 1 (1.1%) each. Figure 3 shows the geographical distribution of the studies. Year of publication ranged from 1981 to 2023 and the year 2019 had the highest number of published articles [9].

Study designs included: quantitative (84.8%); qualitative (13%) and mixed methods (2.2%). Most studies were exploratory: 69.6% explored factors impacting on mental health while 30.4% tested interventions. Of the 92 studies, 98.9% reported a sample size, 88% reported data on gender distribution (males and/or females), 81.5% reported participants' age, 50% reported onset of VI (congenital and adventitious) while 41.3% reported type of VI (mild VI: 25.7%; low vision (including legal blindness): 60.6%; blindness: 13.7%). Overall, a considerable amount of data was missing from most studies with 81.5% not reporting one or more participant characteristics. Fifty-five percent (55%) of studies found protective factors only, 18.5% identified risk factors only and 26.1% identified both protective and risk factors.

The sample size of the studies included ranged from 1 to 7,677. Given that 11 studies were unclear about the gender distribution of their participants, the total number of male (5,735) and female (5,990) participants was less than the total sample size (20,392). Participants ranged from 11-102 years. The type of VI reported included mild VI (952), low vision (including legal blindness (2,249)) and blindness (510). Some studies distinguished between totally blind (no light perception) and low vision while others classified participants living with total blindness and people living with residual vision together. Significant variability was observed in definitions of blindness.

### Thematic analysis

The following section presents the themes and subthemes identified in the evidence which were considered as protective and risk factors for mental health in people living with adventitious VI. These themes and subthemes were systematically mapped to the corresponding layers of the socioecological model as depicted in Figure 4 to explain how contextual and lifestyle factors shape the mental health of the target population. In Figure 4, the protective factor themes are outlined in green boxes while their corresponding subthemes are in yellow boxes. These are factors that improved and/or strengthened mental health, decreased mental health conditions and improved life satisfaction.

Conversely, the risk factor themes are depicted in red boxes, and corresponding subthemes are in yellow boxes in Figure 4. These are factors that are detrimental to mental health, manifested through distress, reduced quality of life, worsening of mental health problems such as depression and other negative impacts.

In this section, we contextualise the protective and risk factors which are presented under the different layers of influence of the socioecological model. Definition

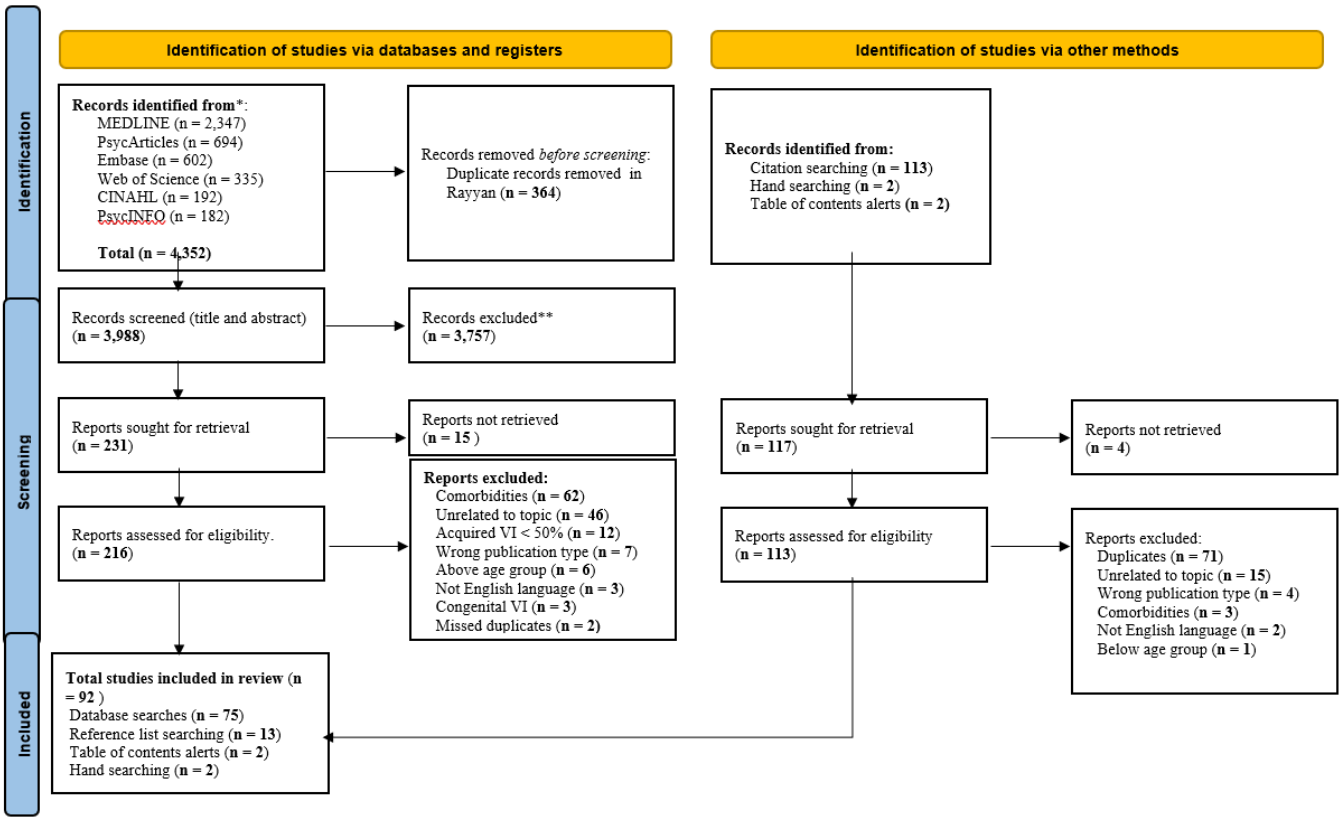


**Figure 2.** PRISMA flow diagram of database searches and other sources. Source: Adapted from [70].

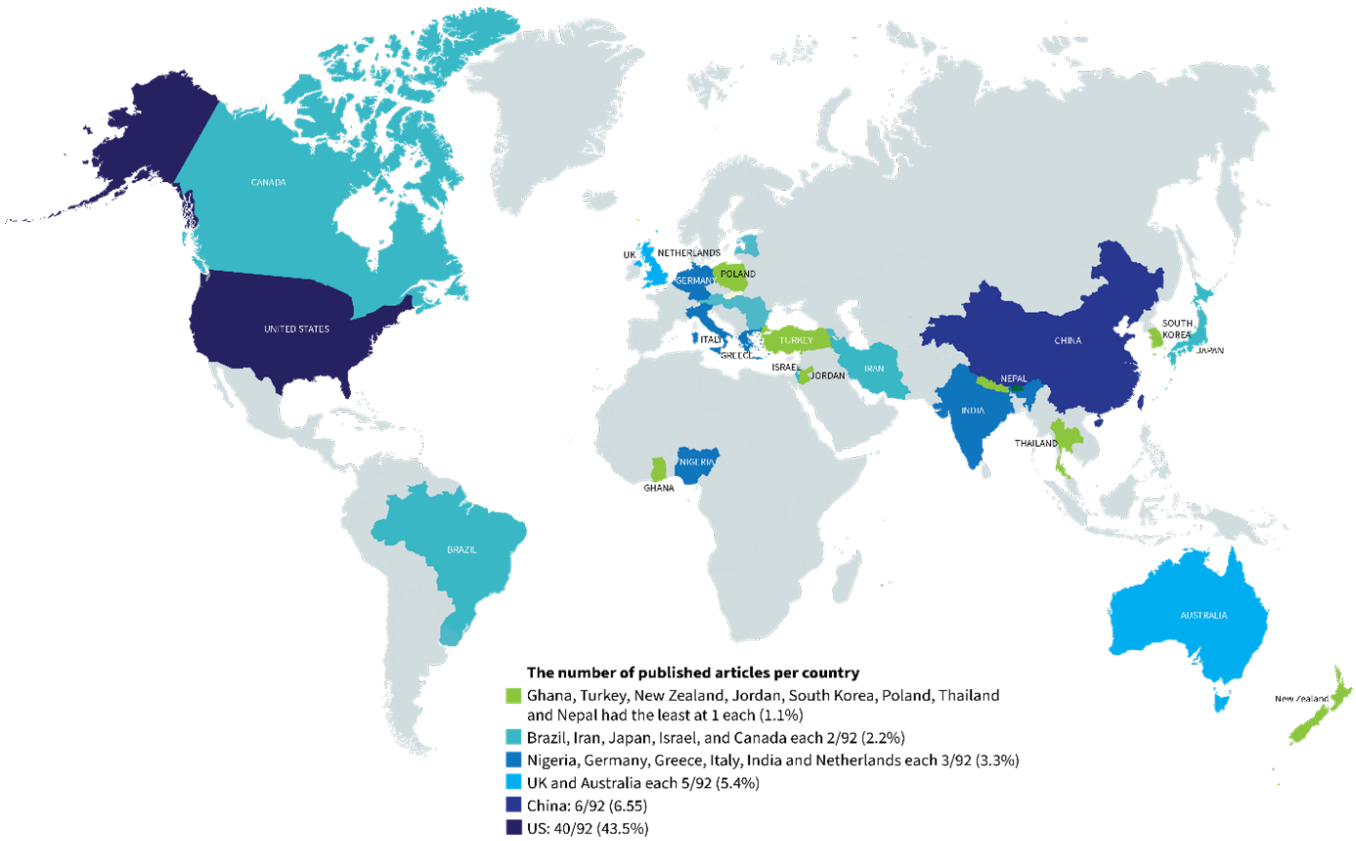


**Figure 3.** The number of published articles per country. Source: Adapted from [71].

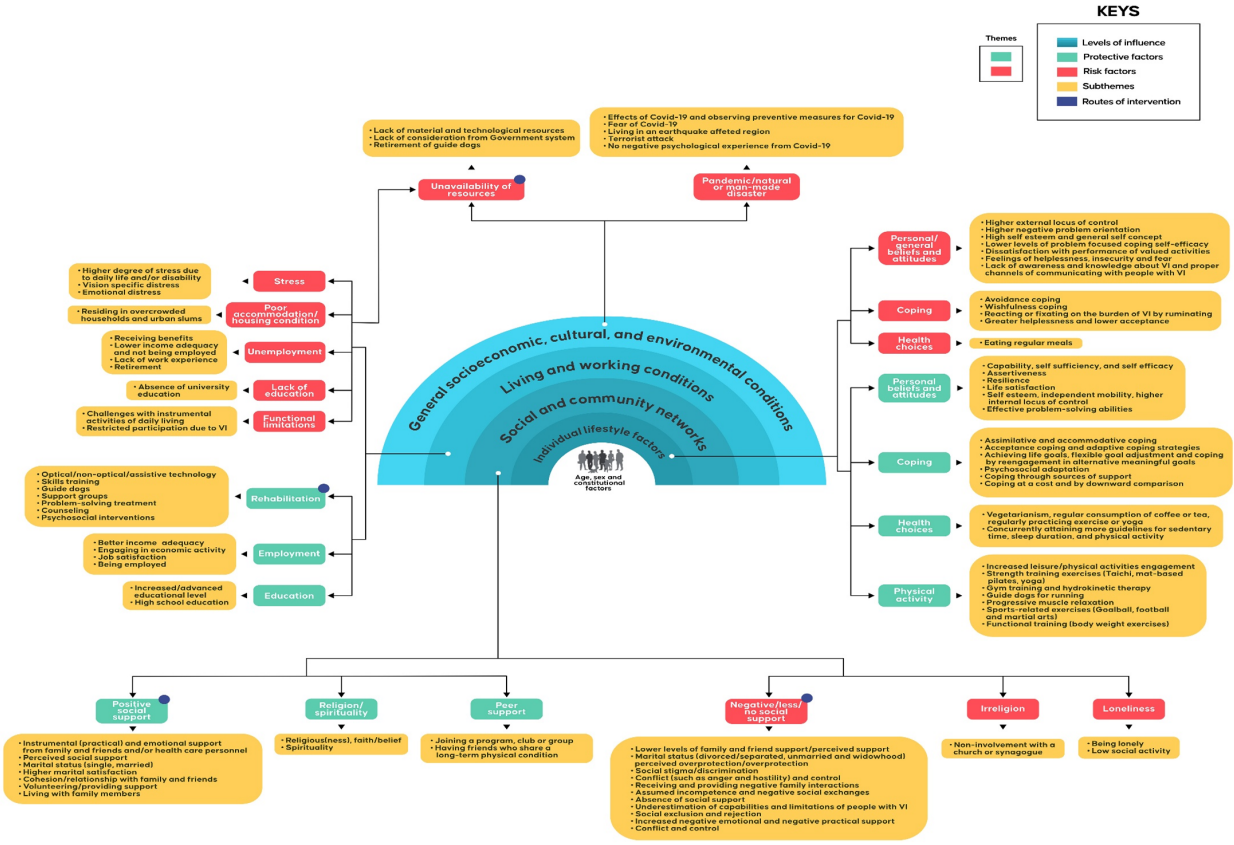


**Figure 4.** Mapping of identified protective and risk factors to Dahlgren and Whitehead's socioecological model. Source: Adapted from [60].

of themes and subthemes are provided in Table 1.

## General socioeconomic, cultural and environmental conditions

### *Protective factors*

Under this outermost layer of influence, none of the included studies reported protective factors for mental health. This outermost layer (General socioeconomic, cultural and environmental conditions) and the innermost layer (Age, sex and genetics) of the Dahlgren and Whitehead's socioecological model were the only layers of influence that did not yield any protective factors in this study.

### *Risk factors*

The theme *pandemic, natural or man-made disaster* was found in five studies (5.4%) with subthemes: effects of Covid-19 and observing preventive measures for Covid-19 [72]; fear of Covid-19 [73]; living in an earthquake affected region [74]; terrorist attack [75] and no negative psychological experience from Covid-19 [76]. In separate studies, *unavailability of resources* was found in three studies (3.3%) and included subthemes: lack of material and technological resources [77]; lack of consideration from the system [76] and retirement of guide dogs [78].

## Living and working conditions

### *Protective factors*

A major predominant theme identified was *rehabilitation*, which the authors operationalised as any organised intervention or training such as therapy and/or acquisition of skills that supports people living with adventitious VI to maintain positive mental health [79]. Twenty-eight (28) studies (30.4%) found *rehabilitation* to be supportive of mental health. These were grouped under various subthemes that include: optical/non-optical/assistive technology [80–90]; skills training [91–96]; guide dogs [97–100]; support groups [96,101,102]; problem-solving treatment [103–105]; counseling [87,106,107] and psychosocial interventions [103]. Another theme under this layer of influence, which was found to be beneficial to mental health in a number of studies (4; 4.3%), is *education*. The subthemes comprised of increased/advanced educational level [108–110] and high school education [73]. Regarding the theme *employment*, four subthemes: better income adequacy [109]; engaging in economic activity [111]; job satisfaction [112] and being employed [113] were identified to be protective of mental health in four studies (4.3%).

**Table 1.** Definitions of themes and subthemes.

| No | Themes and subthemes | Definitions |
|---|---|---|
| 1 | Rehabilitation | A set of measures which aid a person experiencing or likely to face disability in the attainment and retainment of optimal functioning when he/she interacts with their environments [162]. |
| 2 | Problem solving treatment/therapy | Psychological treatment that assists in educating one on effective management of the negative effects of stressful life events [163]. |
| 3 | Social support | Providing comfort and assistance to other people usually to assist them in coping with psychological, biological, and social stressors [164]. |
| 4 | Instrumental support | Assisting with domestic chores, transportation, care during ill-health and provision of housing and monetary assistance to each other [165]. |
| 5 | Emotional support | Verbal and nonverbal ways through which a person shows concern and care for the other person, being empathetic, reassuring, accepting, and comforting [166]. |
| 6 | Coping | The thoughts and behaviour utilized in managing the internal and external demands of stressful situations [167]. |
| 7 | Assimilative coping | This is a strategy to manage stress whereby an individual actively attempts to change a situation to conform to their aspirations and goals [168]. |
| 8 | Accommodative coping | A strategy to manage stress whereby an individual adjusts their orientations and preferences to conform to designated situational constraints and forces [169]. |
| 9 | Acceptance coping | This refers to confronting the reality irrespective of whether it suits an individual's wishes or expectations including the willingness to handle the reality regardless [170]. |
| 10 | Avoidance coping | Any strategic for the management of stressful situation where an individual does not directly address the issue rather, he/she disengages from the situation and turns away from it [171]. |
| 11 | Internal locus of control | When individuals tend to act in response to internal intentions and states and have the perception that their exercise of their own abilities and agency is responsible for their life outcomes [172]. |
| 12 | External locus of control | When individuals tend to act in response to external situations and have the perception that their life outcomes are because of factors outside their control [172]. |
| 13 | Peer support | When individuals who share similar long term health experiences unite to support one another – either on an individual or group basis [173]. |
| 14 | Overprotection | Behavioural pattern where a caregiver usually a parent excessively shields their ward from potential failures, risks, or challenges more than is developmentally needed or appropriate [174]. |
| 15 | Vision specific distress | The type of distress elicited when one copes with VI [115]. |

#### *Risk factors*

Factors under the theme *stress* were researched in five studies (5.4%) with subthemes: higher degree of stress due to daily life and/or disability [111,114]; vision specific distress [115,116]; and emotional distress [117]. Furthermore, *unemployment* as a theme was found in four studies (4.3%) and the subthemes included: receiving benefits [111]; lower income adequacy and unemployed [118]; lack of work experience [119]; and retirement [120]. In three studies (3.3%), the theme *functional limitations* was identified as detrimental to mental health and comprised the subthemes: challenges with instrumental activities of daily living [76,121] and restricted participation due to VI [116]. Here, *unavailability of resources* was also regarded as a theme under this layer of influence and was found in three studies (3.3%) which included subthemes: lack of material and technological resources [77]; lack of consideration from the system [76] and retirement of guide dogs [78]. One study (1.1%) showed that lack of education was detrimental to mental health and included the subtheme: absence of university education [120]. Only one study (1.1%) identified the theme, *poor accommodation/housing condition* with the subtheme: residing in overcrowded households and urban slums [110].

### Social and community networks

#### *Protective factors*

Promotion of mental health was supported by the theme *positive social support*. This theme encompassed subthemes which were identified in 23 studies (25%) and they include: instrumental (practical) and emotional support from family and friends and/or health care personnel [66,109,122–129]; perceived social sup-

port [72,130–132]; marital status (single, married); higher marital satisfaction [108,109,133,134]; cohesion/relationship with family and friends [111,135,136]; volunteering/providing support [109,137,138] and living with family members [108]. Alongside these, four other articles (4.3%) found that the theme *religion/spirituality*, which encompassed subthemes: religious(ness); faith/belief [114,122,139] and spirituality [114,140], were positively associated with mental health. Finally, two studies (2.2%) identified factors under the theme *peer support* and subthemes include: joining a program, club, or group [122] and having friends who share a long-term physical condition [141].

#### *Risk factors*

A recurring theme under this layer of influence was *negative or lack of social support* which was explored in 16 (17.4%) studies and included the following subthemes: lower levels of family and friend support/perceived support [66,111,115,116,118,121,126,130,138]; marital status (divorced/separated, unmarried and widowhood) [111,119,120]; perceived overprotection and/or overprotection [118,123]; social stigma/discrimination [66,142]; conflict (such as anger and hostility) and control [123,135]; receiving and providing negative family interactions [109]; assumed incompetence and negative social exchanges [66]; absence of social support [123]; underestimation of capabilities and limitations of people living with VI [123]; social exclusion and rejection [125] and increased negative emotional and negative practical support [130]. *Loneliness* as a theme was identified in two studies (2.2%) and the subthemes included: being lonely [143]; and low social activity [144]. One other theme identified in one study (1.1%) under this layer of influence is *irreligion* and has a subtheme: non-involvement with a church or synagogue [135].

### Individual lifestyle factors

#### *Protective factors*

The protective factor theme *physical activity* was identified in 12 studies (13%) and comprised the following subthemes: increased leisure/physical activities engagement [110,112,145–148]; strength training exercises (Taichi, mat-based Pilates, yoga) [110,149,150]; gym training and hydrokinetic therapy [92]; guide dogs for running [100]; progressive muscle relaxation [103] and sports-related exercises (Goalball, football and martial arts) and functional training (body weight exercises) [151]. Additional subthemes identified in 10 studies (10.9%) as fostering positive mental health were: assimilative and accommodative coping [31,152]; acceptance coping and adaptive coping strategies [128,153]; achieving life goals, flexible goal adjustment and coping by reengagement in alternative meaningful goals [154,155]; psychosocial adaptation [115,156]; coping through sources of support [122]; and coping at a cost and by downward comparison [67]. These were encompassed under the theme *coping*.

Less frequently reported protective factor themes were varied but covered *personal beliefs and attitudes* and *health choices*. The theme *personal beliefs and attitudes* was identified in seven studies (7.6%) and the subthemes were capability, self sufficiency, and self efficacy [130,145]; assertiveness [124]; resilience [129]; life satisfaction [137]; self esteem, independent mobility, higher internal locus of control [157]; and effective problem-solving abilities [117]. Under the theme *health choices*, vegetarianism, regular consumption of coffee or tea, regularly practicing exercise or yoga [110] and concurrently attaining more guidelines for sedentary time, sleep duration, and physical activity [148] were subthemes supporting positive mental health in two studies (2.2%).

#### *Risk factors*

Under this layer of influence, seven studies (7.6%) found the theme *personal/general beliefs and attitudes* which encompassed the subthemes: higher external locus of control [157]; a higher negative problem orientation [117]; high self esteem and general self concept [133]; lower levels of problem focused coping self-efficacy [158]; dissatisfaction with performance of valued activities [159]; feelings of helplessness, insecurity and fear and [160]; lack of awareness and knowledge about VI and proper channels of communicating with people living with VI [77]. Five other studies (5.4%) identified coping as a theme along with subthemes: avoidance coping [115,161]; wishfulness coping [128] reacting or fixating on the burden of VI by ruminating [155]; and greater helplessness and lower acceptance [158]. Lastly, the *health choices'* theme was found in one study (1.1%) with the subtheme eating regular meals [111].

## DISCUSSION

This is the first scoping review to comprehensively explore protective and risk factors for mental health for people living with adventitious total bilateral blindness and low vision [29]. Despite the higher predisposition of this population to have mental health challenges [4–6,22], research into the determinants of mental health in this population has remained largely fragmented following a siloed approach. This does not give a comprehensive perspective of the research problem, thereby creating a gap in the evidence base. Due to the comprehensiveness of our review, we included 92 studies which yielded extensive results that have important implications for the mental health of our target population. Ultimately, exploring these determinants is critical for a holistic approach in the prevention and management of mental health challenges.

*Rehabilitation* and *positive social support* were the most commonly studied protective factors, supported by the most evidence, suggesting points for intervention. On the other hand, the most commonly studied risk factor was negative social support, similarly suggesting routes for remedial action. In this section, these major find-

ings (rehabilitation and social support) and gaps are discussed.

Many studies identified *rehabilitation* as protective for mental health, and this theme was mapped to the second layer of influence in the analytical model: living and working conditions [59–61]. Supporting evidence has shown that rehabilitation services aid people living with VI to live independently [175]. According to the WHO, It is advantageous to invest in rehabilitation and provision of assistive technologies due to their role in building human capacity [176]. Evidence from the analysis in this review corroborates this. However, unavailability of resources to aid people living with VI, manifesting as a lack of material and technological resources, was also identified in this review as adversely impacting mental health [77]. According to Whitehead and Dahlgren, there are numerous determinants of social inequities in health and one of these is limited access to essential health services [177]. Often, people in the greatest need are those with the poorest access to care [177].

A repeated and persistent theme identified was *social support* which falls under the layer of influence defined as social and community networks [59–61]. As our findings indicate, social support can be both positive and negative. Our results are consistent with findings from Kuettel and Larsen's scoping review on mental health of elite athletes [178]. In their review, positive social relationships, general social support and access to support were protective while lack of social support and negative relationship spillover were potential risk factors for languishing [178]. According to Cimarolli and Boerner, positive and negative forms of social support can coexist in one's social environment as evidenced in our review [123]. For instance, significant others and close friends can offer care and love but also be sources of distress and conflict [179]. This has significant implications for people living with adventitious VI.

Furthermore, most of the included studies that researched social support focused on support from family and friends. This is understandable given that family and friends are usually closest to the people when loss of vision occurs. Hence, the role of providing support often automatically falls on them. When one lives with a chronic disability, reliance on family and friends for instrumental and emotional support is often the norm [123].

Our analysis also revealed that there are many risk and protective factors at all levels (micro/meso/macro) of the Dahlgren and Whitehead's socioecological model which are likely to be in 'dynamic tension' (push-pull depending on context or agency). It is also interesting to note that when progressing through the layers of influence, there appears to be relatively more risk factor themes than protective factor themes. This may imply heavy socially determined effects of mental health in people living with adventitious VI. This finding is significant as it gives a clear understanding of the role communities and society play in shaping the mental health of this population.

One other finding from our analysis is that of inequitable evidence. There was a clear underrepresentation of studies from LMICs even though about 90% of people living with VI reside in LMICs [58]. Our findings concur with a scoping review on protective and risk factors for mental health of elite athletes [178]. Their results indicated an increased research focus on mental health of their target population in Europe and Australia/Oceania while there was less in Asia and none in South America and Africa [178]. Consequently, researchers from LMICs are faced with multifaceted issues in attaining equality in participation and representation in the research community globally [180].

Additionally, through the socioecological lens, socially determined factors hinder adequate visibility of research from LMICs. A study investigating barriers to the decolonisation of global health revealed that factors such as limited technological resources, insufficient support and training, and restriction of access to high impact journals, hindered research productivity and visibility [181]. Moreover, scientists in high income countries have better training on how to navigate the academic research terrain (such as writing of grants and publishing) which has for the most part been rooted in the global North [182]. This negatively impacts on grant applications for LMICs researchers, leading to underrepresentation [182].

A further notable feature of the literature reviewed, was a lack of uniformity in how blindness and low vision were defined across included studies. Due to lack of uniformity in the classification of blindness, research on people living with blindness has often included both groups of persons and more frequently focused on the low vision group thereby obscuring a research problem. This was evident in our review. The majority of the participants had low vision (60.6%) while only a few had blindness (13.7%). Moreover, some included studies labelled some participants with residual vision as 'blind'. Blindness was defined in this review as total absence of light and form perception or total absence of sight [17,18]. However, in the ICD-11, blindness is classified differently in three parts ranging from people living with residual vision through to total blindness [19]. Note that the continued grouping of both types of VI could result in under researching of the people living with total blindness [183].

In addition, when people living with low vision are classified as blind, it may create further confusion as to their visual needs and corresponding corrective measures [184]. In his seminal work, Carroll asserted that there has to be some exact definition of the term, 'blindness' [184]. Suitably, the American Foundation for the Blind has advocated that the word 'blind' should be reserved for those people living without any usable sight [13].

Furthermore, incomplete reporting of basic participant characteristics was rampant in most of the included

studies (81.5%). These studies had one or more missing/unclear relevant data of participants. For instance, the total sample size of the included studies was higher than the total number of reported males and females, due to lack of clarity about the gender distribution of participants in some included studies. In their analysis of a study that involved secondary data, Dina and Berchtold observed that a limitation of using secondary data is a lack of relevant information [185]. Findings from studies with incomplete data on numbers may lead to an underestimation of the problem being researched. This trend is problematic as it does not allow for holistic and accurate reporting and analysis.

### Strengths and limitations

Deductive coding through the application of Dahlgren and Whitehead's socioecological framework may have introduced a predefined bias in the categorisation of protective and risk factors. However, the authors minimised the potential for bias by incorporating inductive coding.

We only included research conducted or translated in the English language. By so doing, we may have omitted some potentially important articles in foreign languages that may have met other inclusion criteria. Nonetheless, a systematic review by Morrison et al found no evidence that English language restriction introduces systematic bias in systematic review results [186].

Additionally, our literature search was conducted in six databases. There may have been potentially relevant studies present in the databases we did not include. However, it is imperative to note that we conducted a robust and comprehensive literature search. We also set up TOC alerts in 17 journals as well as in Google and Google Scholar. Hence, the robustness and comprehensiveness of our literature search elicited 92 eligible studies from which critical and valuable research information were charted and reported.

Minor adjustments were made to the review process in relation to the protocol. According to Peters et al, any change made in the review from the protocol needs to be explicitly stated and clarified [48]. Due to resource and timeline pressures, we decided to be pragmatic within our approach. Only one member of the review team (ND) conducted 100% of the full text screening and data extraction with four members screening a set percentage of the full texts. Any doubts about eligibility were checked with the members of the review team and resolved. Additionally, the extracted data were revised and cross checked by LD, HMM, ZCS and BE. Therefore, the screening process aligned with the best practice expected of high-quality scoping reviews [48], and a pragmatic approach enabled complete reporting.

Additional adjustments pertained to including studies that spanned the age range of 18-65 years, and those that included people living with congenital VI if at least 50% of the study sample consisted of the population of interest. These were practical decisions taken by the authors given that the research focus is an under-researched area where there are a very limited number of studies. Hence, the authors decided to have broader inclusion criteria to address the paucity of the evidence base, by extracting data beneficial to our target population. These adjustments lend credence to the non-linearity of research processes and abilities of the researchers to make pragmatic research decisions.

### Conclusion and recommendations

This review aimed to explore, identify, chart, and report existing literature on factors that promote or adversely impact the mental health of working age adults living with adventitious total bilateral blindness and low vision [29]. We charted and discussed our findings using Dahlgren and Whitehead's socioecological framework on health inequalities [59–61]. Through the socioecological lens, our analysis showed multiple upstream drivers acting singularly and in concert to influence the mental health of our target population.

Our findings emphasize the need for a multidisciplinary approach at the community-level and societal-level, that centralises the wider social, environmental, cultural and economic contexts and the institutional ways the condition and related issues are reported, recorded and researched.

Based on our analysis, we have made the following key recommendations for public health services and research:

#### *For services*

Given the working age status of our target population, occupational rehabilitation should be prioritised, alongside other forms of rehabilitation. Hence, multidisciplinary teams' action is required for a holistic outcome. For instance, such actions can be undertaken by teams comprising of psychotherapists, orientation and mobility specialists, assistive technologists and occupational therapists.

Having acknowledged that every facet of close-knit social relationships is not always positive [179], people living with adventitious VI need to be supported in the development of protective characteristics by means of reducing negative interactions that have been identified, or encouraged to develop alternative relationships [179]. For instance, governments could aim at sponsoring the design and implementation of high-level interventions targeting communities. These include educational programmes where family members (spouses, siblings, parents) and friends are supported and enabled to build skills on how to effectively support people living with VI without compromising the mental health of the target population [123]. Additionally, awareness of these protective and risk factors can promote mental health literacy for service providers and users as well as inform the design and conduct of tailored health programmes to promote and maintain positive mental health [29].

*For research*

There was an underrepresentation of LMICs in the number of studies included in our review. Therefore, to address power imbalances in global health research, LMICs need to take up roles as assertive partners co-financing a joint enterprise [182]. This stance will support the recognition of VI and attendant mental health challenges as it exists in LMICs contexts.

Additionally, Zachariah et al, suggest provision of funding for operational research and more and larger grants for specific research in LMICs [187]. This approach has proven to be successful in Africa. A study evaluated the European and Developing Countries Clinical Trials Partnership which set out to combat poverty-related diseases in Africa [188]. With 64 institutions in 21 countries in Africa, more than 1,000 African scientists have received training and up to 38 peer-reviewed studies have been published by means of networking and partnerships [188]. We therefore join in the calls for better visibility and representation of LMICs in health research through increased and targeted funding, from private and public organizations [187].

Given the inconsistencies in the definition of blindness, we advocate that the WHO review the classification for blindness in further revisions of the ICD. Only people living with total blindness should be classified as blind in the ICD. This could ensure that people living with total blindness are not underreported in research and that their research and rehabilitation needs are given adequate attention. Another study had proposed revisions to the definition of blindness in the ICD, but focused on a less strict definition of blindness due to increasing demands of visual tasks contradicting our proposal for a stricter definition [189]. It remains to be seen if ICD implements either of these proposals in their future revisions.

Furthermore, complete reporting of research characteristics by researchers is best practice and should be mandatory. Considering the substantial amount of relevant study characteristics that were missing from the included studies, we propose that authors of health research be more accountable and explicit in collecting and reporting research to avoid shortfalls and underestimation of a research problem.

Our results showed that most of the included studies were quantitative studies compared with comparatively less qualitative research. Yet qualitative research seeks to generate detailed and rich descriptions of the studied phenomenon and to unravel new meanings and perceptions [190]. Given that mental health was found to be largely determined by social contexts, there is a need for more qualitative research to understand participant perspectives in this area. Future qualitative research can study the impact of these protective and risk factors for mental health through accounts of lived experiences.

Finally, increased likelihood of mental health challenges found in the target population [4–6,22] precipitates a critical need to investigate the adequacy and capacity of health systems to cater to their healthcare needs. The outcome of such research can provide relevant insights into availability and affordability of healthcare for people living with VI.

# DECLARATIONS

### AI utilization
Not applicable.

### Competing interests
The authors have declared that no competing interests exist.

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Project administration: ND; Supervision: LD, HMM, ZCS, BE; Methodology: ND, LD, HMM, ZCS, BE, MA; Data curation: ND, LD, HMM, ZCS MA; Formal analysis: ND; Resources: ND; Visualization: ND; Writing – original draft: ND; Writing – review & editing: ND, LD, HMM, ZCS, BE, MA

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## ABSTRACT IN SPANISH

**Promoción y protección de la salud mental de personas con ceguera adquirida y baja visión: una revisión exploratoria de factores protectores y de riesgo**

**Introducción:** Las personas que viven con discapacidad visual (DV) presentan una mayor prevalencia de problemas de salud mental en comparación con quienes no tienen DV. Se ha estimado que la depresión clínica afecta entre el 10 y el 40% de esta población. En particular, los adultos en edad laboral (18 a 65 años) con DV adquirida tienen un mayor riesgo de sufrir malestar psicológico grave, interrupciones en su situación laboral y la consecuente pérdida de ingresos. Por ello, nuestra pregunta de investigación fue: ¿Qué se sabe, según la literatura existente, sobre los factores protectores y de riesgo para la salud mental de adultos en edad laboral (18 a 65 años) con ceguera bilateral total adquirida y baja visión?

**Métodos:** Siguiendo las directrices del Instituto Joanna Briggs, se realizó una búsqueda sistemática de artículos en inglés en seis bases de datos: MEDLINE, PsycINFO, CINAHL, EMBASE, PsycArticles y Web of Science. También se hicieron búsquedas en sitios web como World Blind Union, World Vision, African Union y Royal National Institute of Blind People. Dos revisores evaluaron de forma independiente los títulos y resúmenes, y luego todo el equipo revisó los textos completos. De 4.352 títulos identificados, se incluyeron 92. Analizamos la evidencia de manera temática utilizando enfoques inductivo y deductivo, este último guiado por el modelo socioecológico de Dahlgren y Whitehead.

**Resultados:** Se identificaron trece temas de riesgo y diez temas protectores. La rehabilitación (factor protector) fue el tema más frecuente en 30,4% de los estudios, seguida del apoyo social negativo (factor de riesgo) con 17,4%. Gran parte de la investigación se realizó en Estados Unidos (43,5%). Entre los hallazgos clave destacan: la fuerte influencia social en la salud mental, la coexistencia de apoyo social positivo y negativo, y la escasez de estudios sobre experiencias vividas. El análisis también reveló varias formas de infrarrepresentación y mala caracterización, incluida la escasa investigación en países de ingresos bajos y medianos, la falta de uniformidad en las definiciones de ceguera y la insuficiente descripción de las características de los participantes.

**Conclusión:** Esta es la primera revisión exploratoria que analiza de forma integral los factores protectores y de riesgo para la salud mental de personas con ceguera bilateral total adquirida y baja visión. El estudio muestra múltiples determinantes estructurales que actúan de forma individual y conjunta, influyendo de manera profunda en la salud mental de la población objetivo. También destaca las formas institucionales en que esta condición y sus temas relacionados se informan, registran y estudian.

**Palabras clave:** Ceguera adquirida, baja visión, bienestar mental, visión parcial, factores protectores, factores de riesgo

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