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Major review

The impact of strabismus on quality of life in adults with and without diplopia: a systematic review

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ABSTRACT

Strabismus affects approximately 4% of the adult population and can cause substantial physical disturbance and changes to appearance. We examine the impact of strabismus in adults both with and without diplopia, focusing primarily on quality of life (QoL). We highlight the value of measuring QoL, assess the ways in which it can be measured, and the impact the disease, diplopia, and surgery have on the patient. QoL differs for strabismus patients based on their diplopia status. Patients with diplopia tend to have more concerns relating to functional QoL, whereas patients without diplopia have primarily psychosocial concerns. Two diplopia-specific questionnaires have been designed to assess QoL and the perceived severity of symptoms. Further research is needed to identify the variables which influence QoL so that appropriate support can be given to all patients with strabismus to improve their QoL.

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1. Introduction

Because of the appearance and physical disturbance experienced by patients with strabismus, quality of life (QoL) can be affected. This may be a result of an inability to perform normal activities, but also may be the result of the psychological distress associated with strabismus. It is therefore important to explore the QoL of patients with strabismus and the additional impact of diplopia.

The concept of QoL is increasingly recognized as an important measure in health care and can be defined as an individual's evaluation of his or her overall well-being and life experience, which is influenced by physical, psychological, social, and environmental factors. QoL is a complex concept with individual assessments varying widely between people with the same illness and within an individual over time.

We shall review the prevalence and treatment options for strabismus, provide an overview of the measurement tools

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used to assess the impact of strabismus on QoL, and summarize published research on the QoL of patients with strabismus, including a comparison of those with and without diplopia. Finally, we shall look at the impact of treatment for strabismus on QoL and the additional impact of double vision.

2. Strabismus and diplopia

The estimated prevalence of strabismus in adulthood is 4%,³ 65% of which develops in childhood.¹⁶ Although the prevalence of strabismus with diplopia is unknown, diplopia is common if strabismus develops after the age of visual maturity.⁴⁰ The main aim of strabismus management is to restore normal ocular alignment and reduce diplopia, if present, allowing the patient to carry out normal daily activities. There are various treatment options for a patient with strabismus that include both surgical and nonsurgical approaches, including pharmacological. Other nonsurgical treatments include refractive correction, vergence exercises, prism therapy, or ocular occlusion. Injection of Botulinum toxin type A causes temporary paralysis of extraocular muscles and results in short term improvement of the deviation. Surgery aims to re-establish ocular alignment, thereby eliminating diplopia. Transient diplopia, however, is present in approximately 9% of all patients post surgery and persists in around 0.8%.²⁶

3. Why measure quality of life?

The impact of disease is traditionally assessed using a biomedical model, with clinical outcomes used as measures of success. Although improving health through the treatment and curing of illness and its associated symptoms is the primary goal of medicine, there is also a need to address patient well-being. Clearly, disease and illness—whether acute or chronic—have an impact on a person's physical, psychological, and social well-being. QoL measures aim to encapsulate this. QoL is multi-dimensional and dynamic, varies between individuals with the same illness and within an individual over time,⁹ in response to various factors.⁶ The aims of measuring QoL are to understand the multidimensional impact of disease, aid in the development of interventions to improve well-being, guide decision making, and direct allocation of resources and health care policy. Those with a good QoL at the start of treatment are likely to fare better than those with a poor QoL at the start of treatment, making QoL an effective prognostic indicator. Physicians may underestimate the impact of ophthalmic conditions on a patient's QoL.⁴¹ This may be as a result of inadequate communication and could lead to impaired treatment decision making and poor outcomes. When different treatment options are available, a full discussion on the most appropriate intervention can only be undertaken if data has been collected on the possible benefits to an individual's QoL.

Despite assumptions by the medical community, the relationship between symptom or disease severity and QoL is not consistent.²⁵ Not all patients experiencing severe symptoms or illness report poor QoL, but those with minor symptoms may.⁶ This highlights not only the personal evaluative

nature of the concept but also the need to make individual assessments. If symptom or illness severity cannot explain poor QoL, other factors must play a role. These may include demographic, functional, psychological, and social concepts along with treatment.

Study of other acute and chronic conditions has revealed a number of intervening cognitive processes that may mediate the relationship between demographic and clinical variables and QoL (see Fig. 1). Factors include an individual's perception of their illness and its treatment, levels of psychological well-being such as anxiety and depression, and more generalized psychological concepts such as perceived social support.^{4,35} For strabismus that impacts appearance, a person's cognitive representation of themselves and how they look may also play a role. Psychological adjustment may be more difficult when individuals place greater value on how they look rather than on personal qualities or abilities, particularly if they feel unattractive. This is particularly true for people prone to compare themselves to others,¹⁷ who have a fear of receiving negative comments, and who believe their disfigurement is highly visible. The identification of these issues is vital in the understanding of QoL and the development of psychosocial interventions to promote positive adjustment.

4. Measuring quality of life in strabismus

QoL is defined in different ways, and measurement poses many challenges. Some QoL questionnaires are unidimensional, whereas others measure various aspects of QoL. The choice of questionnaire depends on the reasons for measurement and the primary concepts of interest. Measures are also divided into those that are generic and those specific to a particular condition. Generic measures will be more appropriate when a study examines more than one disease group. Common generic measures widely used in strabismus research include the group of short form health surveys (SF8, SF12, and SF36) and the EQ-5D that is predominantly used for economic analysis. The SF36, arguably the most frequently used generic QoL outcome measure, provides an eight-scale profile of functional health and well-being (physical, social, and emotional functioning; pain; mental health; vitality; general health; and role limitations) as well as composite mental and physical health summary scores. The EUROQoL EQ-5D is a brief QoL questionnaire that allows assessment of health status in a wide range of health conditions and treatments and is currently one of the key measures in the Patient Reported Outcome Measurement program conducted by the Department of Health in England. Although these measures allow comparisons between conditions, they fail to capture the specific impact of strabismus and its associated symptoms and are not sensitive to small, but clinically significant, changes in QoL over time. Vision-specific instruments have therefore been developed that focus on areas important to patients with ophthalmic conditions and are considered more sensitive than generic disease measures.⁴³ These include the Visual Function Questionnaire²⁹ (VFQ-25), a shortened version of the National Eye Institute Visual Function Questionnaire³⁰ (NEI-VFQ), and the 14-item Visual Function questionnaire⁴² (VF-14). Although not specific to strabismus, these capture in part the impact of visual disturbances.

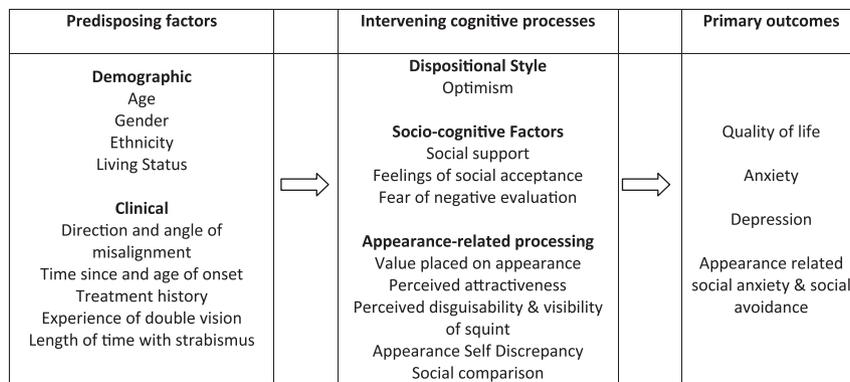


Fig. 1 – Framework of psychological adjustment to strabismus.

The VFQ-25 measures vision-related QoL and looks at the influence of visual disability and visual symptoms on generic health domains, such as emotional well-being and social functioning, in addition to a task-orientated domain specific to daily functioning. The measure consists of eight unidimensional subscales (difficulties with near distance activities, limitations in social functioning, role limitations, dependency on others, mental symptoms, driving difficulties, limitations with peripheral and color vision, and ocular pain). Developed in collaboration with groups of condition-specific patients, the VFQ-25 contains few items relating to strabismus-specific issues (such as appearance) and more specific psychosocial concerns. Although the VFQ-25 identifies poorer QoL in patients with diplopic strabismus as they have more vision-related difficulties, it has a weaker discriminatory ability in non-diplopic patients.²⁰ This measure does, however, respond to improvements in QoL after successful surgery²⁰ and has excellent test–retest reliability. It is prone to ceiling effects, however, as adults with strabismus cluster towards the normal end of the range.²⁷

The VF-14, an index of visual function for those undergoing cataract surgery,⁴² has been used in a number of ophthalmic groups, but is yet to be validated in strabismus. Items include the ability to read; do fine handwork; drive; write checks or complete forms; watch television; participate in sports and table games; see steps, stairs, or curbs; cook; and recognize people at close distances.

Strabismus-specific QoL questionnaires cover more comprehensively the range of problems faced by individuals with the condition. Carlton et al⁸ identified four strabismus- and amblyopia-specific QoL questionnaires: the amblyopia and strabismus questionnaire⁴⁶ (A&SQ), the amblyopia treatment index,¹¹ the adult strabismus questionnaire¹⁹ (AS-20), and the intermittent exotropia questionnaire.²² The two strabismus-specific questionnaires, the A&SQ and AS-20, have both been shown to have better discriminatory ability when compared with the SF-12 and VFQ-25^{18,46} for those with strabismus.

The 26-item patient-derived Dutch-language A&SQ and its English-language version¹⁴ (ASQE) were designed to capture the QoL of amblyopia and/or strabismus patients. The measures consist of five subscales (distance judgment and depth perception, visual confusion, diplopia, appearance-related and social difficulties, fear of loss of sight in the better eye). They possess good internal consistency and construct validity, and are discriminatory and concurrent.^{44,45}

In an attempt to identify the effects of amblyopia separately from strabismus utilizing modern measurement theory, Vianya-Estopa et al⁴⁷ found that many of the strabismus subgroup items were not normally distributed and had significant skew, mainly as a result of high ceiling effects. In addition, a number of participants had difficulty with a large majority of the items and with some of the scale labels. They therefore suggested a reduction from a 5-item to 3-item Likert scale, which improved discriminative ability. Although all items did appear appropriate for individuals with strabismus, they suggest that separate instruments for amblyopia and strabismus are needed.

Many of these concerns have been addressed in the development of the AS-20. Using extraction techniques, items were created from phrases in patient interviews.²¹ A total of 181 items were then completed by a group of strabismus patients and then reduced to 20 items using factor analysis.¹⁹ The two subscales of psychosocial concerns and functional difficulties possess good discriminative ability, internal consistency,¹⁸ and test–retest reliability.²⁷ Sensitivity is also greater than the VFQ-25¹⁸ and is responsive to change post surgery.²⁰

Overall, the QoL of patients with strabismus can be measured using instruments with good validity and reliability, at a low cost and in minimal time. Therefore, measurement of QoL does not need to be confined to research, but should be encouraged in everyday practice to allow for the appropriate and timely discussion about the impact of the condition on patients and also for the prescription of treatment.⁸

5. The impact of strabismus on quality of life

Appearance has enormous influence on psychosocial functioning,³⁶ and the eyes in particular play an important role in perceived attractiveness and communication.¹⁰ Unsurprisingly, ocular misalignment has considerable impact on QoL.

Sabri et al³⁸ looked at the impact of strabismus and amblyopia using the VF-14 in a group of 120 teenagers and found a significantly poorer QoL in teenagers with amblyopia compared to those with normal vision, but found no significant differences when comparing those with and without cosmetically noticeable strabismus. In addition, there was no relationship between the angle of the squint and QoL,

supporting the view that clinical measures of strabismus are unrelated to psychosocial outcomes.

As part of the ASQE development, van de Graaf et al⁴⁶ compared a group of current amblyopia and/or strabismus patients with healthy controls and a group with strabismus treated 30 years previously. Healthy controls had the best QoL and current outpatients had the worst, not only on the ASQE, but also on the SF-12 and VFQ-25. Current patients had the most difficulty in distance estimation, visual disorientation, diplopia, social contact, and cosmetic problems. Those treated 30 years previously had better QoL compared with current patients, but still had difficulties with social contact, cosmetic concerns, and dealing with fear of losing the better eye. Although it is unclear how many of the historic cohort had recurrent misalignment, these findings suggest that a person's QoL can still be affected despite treatment. Subsequent analysis of the historic sample⁴⁵ found that QoL was significantly associated with the level of visual acuity, both before and immediately after surgery as well as 30 years later. Current assessments also showed that better binocular vision was significantly associated with better QoL; there was no relationship with the angle of deviation, however.

Some have argued that separate questionnaires for amblyopia and strabismus would be more informative,^{21,38} van de Graaf et al⁴⁵ found it was difficult to separate these two conditions, however. In a cross-sectional paper to validate the ASQE in English, Felius et al¹⁴ reported an association between diminished QoL and greater disability. Younger participants reported greater concern about social contact and appearance, as did young women who also scored significantly worse on visual disorientation and double vision. Improved QoL was associated significantly with lower levels of unilateral acuity loss, diplopia, and asthenopic symptoms. Similarly, adults with strabismus have significantly poorer QoL compared to visually normal adults^{13,19} and adults with other eye conditions including cataracts, cornea, and glaucoma,¹⁹ but no difference was found between esodeviation and exodeviation.^{12,13}

In addition to the clear impact strabismus can have on a person's QoL, adults with strabismus experience higher levels of anxiety and depression^{23,24} and report low self-image, self-esteem, and self-confidence,^{24,31,39} commonly describing themselves as "stupid", "ugly", and "different".²⁸ Strabismus may affect eye contact and make social communication awkward both for the individual with strabismus and the person interacting with them. As a result social functioning can also be impaired, with higher rates of social phobia and problems with social interactions reported in strabismus.^{5,31} Patients often attribute these difficulties to their strabismus^{7,31} and as a result adopt behaviors to conceal their eyes.^{28,31,33} In fact, some even express willingness to trade in part of their life expectancy in return for being rid of strabismus.¹

Demographic variables such as being female, younger, from a lower socioeconomic strata, being more disabled, having lower levels of visual acuity, higher social anxiety, and avoidance of social situations are associated with poorer QoL. Strabismus can also have a negative effect on other aspects of a person's well-being, such as body image and confidence and as a result impact on their social and concealment behaviors.

5.1. The role of diplopia

The majority of studies exploring the impact of strabismus on the QoL fail to make a distinction between patients with and without diplopia. The limited literature on this topic does, however, suggest there may be a difference between these groups.

In a qualitative exploration of how strabismus affects every day life,²¹ analysis of 30 interviews revealed that patients with diplopia mainly report concerns with physical functioning, general disability, and difficulties performing vision-related roles. In contrast, patients without diplopia predominantly revealed concerns about physical appearance, social relationships, difficulties in communication, and eye contact. In other studies patients with diplopia more frequently mention visual disorientation and difficulties with daily activities,^{1,18} such as driving and walking. Diplopia may heighten physical disability and therefore psychosocial difficulties may be less of a concern. There is, however, a number of common concerns across the two groups. These include the adjustments needed to cope with strabismus, concerns about appearance, driving, work and finances. All patients describe efforts to reduce symptoms; problems with general visual function; nonspecific negative feelings including resignation; and problems with self-confidence, self-consciousness, and self-esteem.

Quantitative research supports these observations. Hatt et al¹⁸ found that significantly more non-diplopic patients scored below normal on the psychosocial subscale, whereas more patients with diplopia scored below normal on the function subscale of the AS-20. These results have been replicated by other authors.^{14,19,27}

Diplopic status maybe an important factor affecting QoL for patients with strabismus. Although people report a mixture of both functional and psychosocial concerns, those with diplopia tend to have concerns primarily about function and those without diplopia, psychosocial concerns.

6. Impact of strabismus surgery on QoL

Concerns over appearance are one of the major reasons patients choose strabismus surgery.³¹ The goal of treatment for the clinician, however, is often to "correct or reverse a pathogenic condition, not to enhance appearance"³⁷ (p 250). As such strabismus surgery is considered to be restorative or reconstructive, rather than cosmetic.³⁷ These differing views may explain why the assessment of surgical success may be different for the patient and surgeon.² Beauchamp et al² retrospectively reviewed 85 patient and physician paired responses to surgery. Both patients and physicians rated the severity of the strabismus as significantly lower post-surgery; the improvement rating, however, was significantly greater for the physician than the patient. When comparing the subgroup of patients who were successfully realigned (defined as ≤ 8 prism diopters of horizontal deviation and/or ≤ 2 diopters of vertical deviation in the primary position) to those that were not, the physicians gave significantly better improvement ratings, but there was no significant difference between the two groups. In fact, surgery appears to have mixed effects for

some patients, with 84% believing that their eyes were still not aligned,³⁹ highlighting the possible persistent effect on QoL.

There is a paucity of good quality research looking at the effects of strabismus surgery on QoL. Limitations include the use of inappropriate, non-validated questionnaires, participant selection bias, and poor study design. To date only four prospective studies have used validated QoL measures.

In the development of the AS-20, Hatt et al²⁰ looked at the responsiveness of this scale and the VFQ-25 to surgery. Clinical criteria were used to classify postoperative outcomes as a success, partial success, or failure. They found that both the AS-20 and VFQ-25 were responsive to change in ocular alignment and symptoms after surgery, suggesting significantly greater postoperative improvement in successfully aligned patients compared with partial success and failures. Although in a small sample, Jackson et al²³ conducted the most methodologically robust study. Measures were completed by all participants pre-surgery and again 6 weeks and 3 months postoperatively. Significant improvements from pre- to post-surgery were found in the physical and psychological QoL domains, but not for social or environmental concerns.

Fujiike et al¹⁵ analyzed the cost-utility of strabismus surgery by balancing the financial costs with the gain in QoL. Expressing QoL in this manner allows for comparison with other ophthalmologic conditions. QoL was prospectively assessed using both the SF-8 and VFQ-25 in those with concomitant and noncomitant strabismus, preoperatively and again 3 months after surgery. In a sample of 226 participants, all subscales of the VFQ-25 improved significantly from pre to post surgery. Scores on the SF-8 were less consistent, but did indicate improvements primarily in the physical QoL subscales for the noncomitant group and the emotional and social functioning subscales for the concomitant group. Using these results and based on the life expectancy of these patients, this surgery resulted in positive gains in regards to QoL and good cost-effectiveness. This study is limited by the potential recurrence of misalignment; therefore, the calculated gain 3 months after surgery may not persist in the long term.

Nelson et al³³ looked at psychosocial concerns and satisfaction pre and post realignment surgery in 128 teenagers and adults. Prior to surgery over 80% of patients reported embarrassment, trouble making eye contact, and self-esteem issues. Following surgery, 98% of patients were satisfied with the alignment. A majority of patients reported improvements in their self-esteem and in their ability to meet new people; only 27% saw improvements in interpersonal relationships and only 16% felt able to try new activities, however. Women benefited more than men. The authors only report descriptive statistics for this sample, and the authored-designed questionnaire lacked specificity in the response scale.

There are also a number of retrospective studies. Burke et al⁷ recruited 31 patients and asked them to retrospectively rate their personality in seven situations. The participants felt that overall their surgery had significantly improved their psychosocial functioning and that people viewed them in a more favorable light as a result of surgery. As in the previous study, the beneficial effects of surgery on QoL would appear to be greater for females compared to males. Using the same questionnaire, two other retrospective studies found realignment surgery had mixed results. In a sample of 101 patients,

Beauchamp et al³¹ found significant improvements after surgery in the seven psychosocial QoL subscales that included the ability to undertake daily tasks and to work, social interactions, eye-specific health problems, and self-image. One group, however, reported no change and for some even a deterioration in these areas. Similar results have been reported elsewhere.³² Menon et al³¹ measured neuroticism pre and post surgery using a semi-structured interview. Forty participants completed these measures and, although they report that seven of the participants experienced lower levels of neuroticism post surgery, there are no details as to whether these reductions were statistically significant. Participants were asked to rate the impact surgery had had on their appearance, relationships with friends, self-esteem, future plans, and social avoidance. Significantly more participants felt there had been positive improvements; the measurement tool, however, did not allow participants to report deterioration.

Several studies have explored the relationship between objective measures of ocular deviation and QoL before and after surgery, with mixed results. Preoperatively, Jackson et al²³ found that anxiety, depression, QoL, and self-reported noticeability of the squint were all correlated significantly with objective misalignment. Postoperatively, however, objective misalignment failed to correlate with QoL and mood. Similarly, objective measures of the size of deviation, such as pre- or postoperative prism cover test (PCT) scores or the change in PCT scores, were not correlated with the degree of psychosocial improvement.^{7,23} In contrast, Nelson³³ report greater benefits for patients with deviations ≥ 25 prism diopters. In general, these studies indicate that there is no clear relationship between the severity of strabismus and the degree of psychosocial distress experienced by patients postoperatively.

There are also conflicting findings about the impact of the different types of strabismus. Burke et al⁷ report that esotropes benefit more from surgery than exotropes. Conversely, Jackson et al²³ found that exotropes showed a greater improvement in coping after surgery.

Overall, these studies suggest improvements in QoL following surgery, but there remains variation, with some patients reporting deterioration. The relationship between QoL and changes in objective measures of misalignment is unclear. Further research is needed to identify which factors impact upon psychological adjustment after treatment. Many of the studies conducted have poor designs, use inadequate measurement methods, and potentially bias results by asking participants to report retrospectively any preoperative problems. Additionally, the measurement tools lack validity and reliability. Generalization is limited as several of these studies included only patients with angles between 25 and 30 prism diopters, leading to a significant selection bias.^{7,31,33}

6.1. The role of diplopia

Strabismus surgery retrospectively restoring ocular alignment may successfully treat diplopia.³⁴ This is not always the case, however. In a recent prospective study, only 57% of patients with diplopia were found to have had no diplopia postoperatively.²⁰

Studies using validated QoL measures explore the differences between the post-surgical outcomes of those with and without double vision. Although mean eye misalignment reduced substantially, from 33.72 prism diopters to 8.52 prism diopters in the sample reported by Jackson et al,²³ of the 18 preoperatively diplopic participants, 11 still had some diplopia postoperatively and one participant with diplopia postoperatively was non-diplopic preoperatively. Patients without diplopia showed postoperative improvements in most psychosocial variables, with significant reductions in depression, anxiety, social anxiety, and avoidance, and improvements in QoL. In contrast, patients with preoperative diplopia showed significant improvements mainly in functional aspects, specifically in relation to reduced eyestrain and headaches, but also in relation to social anxiety and avoidance of social interactions. Of the 106 participants recruited ~~conducted~~ by Hatt et al,²⁰ 80 had diplopia. When compared with failures, successfully aligned patients with preoperative diplopia had a larger improvement, but mainly in functional QoL. For those without preoperative diplopia when compared with unsuccessful surgery, appropriately realigned patients showed significant improvements in mainly psychosocial and some functional QoL subscales.

Surgery can be effective in eliminating diplopia in a considerable proportion of patients, enabling them to perform vision-dependent activities, such as reading and driving, which were previously difficult for them, and also improves the psychosocial well-being of both those with and without diplopia. Conclusions at this time, however, are tentative; further studies with more robust methodology and larger sample sizes are needed to confirm these findings.

7. Conclusion

Strabismus has an impact on the QoL of adult patients. The majority of studies, however, do not differentiate between those with and without diplopia. Studies to date have identified some differences between these groups. Patients with diplopia have a reduced QoL primarily in physical functioning, whereas domains such as psychological, emotional, and social functioning are less of a problem. Strabismus patients without diplopia have more psychosocial concerns. Additional research in this area using validated strabismus-specific measures would help to identify the variables influencing QoL in patients with and without diplopia, so that individual concerns can be better understood and interventions tailored appropriately. Physicians and patients differ in their assessment of the severity of strabismus and in what is a successful surgical outcome. Further research in this area would allow a better understanding of what patients desire from surgical intervention and also how they can be helped to manage the impact of the condition on their psychological well-being.

8. Method of literature search

A systematic literature search was undertaken in March 2011. The major search terms included *strabismus*, *diplopia*, *quality*

of life, *surgery* and *adult*, with varying combinations, Booleans, and MeSH terms depending on the database. The electronic databases searched were Embase, Medline, and PsycINFO from inception to March 2011. No date or language restrictions were applied to the searches but only those with English language full articles or abstracts were included in the review. In addition a hand search of *The American Orthoptic Journal* and the bibliographies of included studies were also undertaken. Duplicates were removed, as were case studies, animal studies, conference abstracts, letters, and editorials. Two authors (HM, CA) independently evaluated the search results using the given inclusion and exclusion criteria. In the case of disagreement, differences were resolved through consensus.

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