Self-perception and self-concept of children and adolescents with Down Syndrome: a scoping review

Autopercepção e autoconceito de crianças e adolescentes com Síndrome de Down: uma revisão de escopo

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ABSTRACT

Objective: the self-concept is the set of attitudes and values about oneself. Self-perception, on the other hand, is understood as a multidimensional construct composed of several domains of the human being. Considering people with Down
Syndrome, this scoping review maps evidence on self-perception and self-concept in children and adolescents with Down Syndrome. Method: this review followed Arksey & O’Malley’s proposal and The Joanna Briggs Institute Manual for Evidence Synthesis. The proposed research question was: “What is the self-perception of children and adolescents with Down Syndrome? The protocol was registered at Open Science Framework (osf.io/znp7j). Results: the search was performed in September 2021, in seven databases, totaling 2437. After screening, seven articles were included, which were grouped considering the complexity of the concepts of self-perception and self-concept. Thus, the synthesis encompassed the following themes: a) body influence; b) social preferences; c) lifestyles and personal achievement; d) school environment. Conclusion: the result of this systematic review suggests that the body and lifestyles of children and adolescents with Down Syndrome influence the self-concept and self-perception of these individuals.

Keywords: adolescent, down syndrome, self-concept.

1 INTRODUCTION

Down Syndrome (DS) is a genetic imbalance, associated with the presence of one or part of an extra chromosome in the chromosome pair 21 (Kosmidou, Tragiannidis, Gavrillaki, 2023). The condition is one of the most prevalent causes of disability in the world, affecting approximately 1 in 650 to 800
live births worldwide and leading to a variable degree of intellectual retardation, in addition to associated specific orofacial features, such as brachycephaly and hypoplastic maxillary sinuses (Rivas-Almonte, Cruz-Escalante, Delgado-Bocanegra, 2021).

Individuals with DS, in general, as well as typical subjects, build their relations between their bodies and the world from their life experiences, environment, and culture. Thus, it is necessary to understand the meaning that the body has for each individual. Body satisfaction and self-perception are primordial in people's self-acceptance and can generate attitudes that interfere in their way of relating to the world around them (Holanda, Cavalcanti, Baltar, Xavier, Gomes, Almeida, 2020).

There is no universally accepted definition of self-concept and self-perception. For this reason, for this review we adopt the referential that self-concept is the set of attitudes and values, which is a broad definition. This is because historically the term covers many aspects of human behavior, such as the self-social, the self-ideal, the self-transitory. Self-perception, on the other hand, is understood as a multidimensional construct composed of several domains of the human being, such as bodily, sexual, social, affective (Begley, Lewis, 1998). In view of this, the aim of this scoping review was to summarize the literature on self-perception and self-concept in children and adolescents with Down Syndrome.

2 METHOD

This scope review followed the 5-step methodology (Arksey, O’malley, 2005) and the Johanna Briggs Institute Manual for Evidence Synthesis (Peters, 2017). The writing of the article was guided by Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) Checklist (Tricco, Lillie, Zarin, O’Brien, Colquhoun, Levac, 2018). Methods were registered in the Open Science Framework platform (osf.io/znp7j).
STEP 1: IDENTIFYING THE RESEARCH QUESTION

Based on the importance of understanding the self-perception and self-concept of children and adolescents with Down Syndrome for the inclusion of these individuals in society, the proposed research question was: “What is the self-perception of children and adolescents with Down Syndrome?

STEP 2: IDENTIFYING RELEVANT STUDIES

The searches were carried out by two independent evaluators in the electronic databases VHL/Lilacs, Cochrane Library, Embase, Pubmed/Medline, Scielo, Scopus and Web of Science. The Medical Subject Headings (MeSH) was used to define the descriptors used in the searches. The Medical Subject Headings (MeSH) was used to define the descriptors used in the searches. The medical subject headings (MeSH) was used to define the descriptors used in the searches. The searches were carried out considering the following descriptors: Body Image/Body Dissatisfaction/ Body Integrity/Identity Disorder/Self-Perception/Self-Concept/Self-Perception// Down Syndrome/Trisomy 21. The search strategies were adapted considering the specificities of each database, according to chart 1.

<table>
<thead>
<tr>
<th>Database</th>
<th>Search strategy</th>
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<tbody>
<tr>
<td>VHL/Lilacs</td>
<td>(Self-Concept) OR (Perception) AND (Down Syndrome)</td>
</tr>
<tr>
<td>Cochrane Library</td>
<td>(body image OR body dissatisfaction OR body integrity OR identity disorder OR self-perception OR self-concept OR self esteem) AND (down syndrome OR trisomy 21)</td>
</tr>
<tr>
<td>Embase</td>
<td>(body image OR body dissatisfaction OR body integrity OR identity disorder OR self-perception OR self-concept OR self esteem) AND (down syndrome OR trisomy 21)</td>
</tr>
<tr>
<td>PubMed/MEDLINE</td>
<td>(body image OR body dissatisfaction OR body integrity OR identity disorder OR self-perception OR self-concept OR self esteem) AND (down syndrome OR trisomy 21)</td>
</tr>
<tr>
<td>Scielo</td>
<td>(Self-Concept OR Perception) AND (down syndrome)</td>
</tr>
<tr>
<td>Scopus</td>
<td>(Self-Concept) OR (Perception) AND (Down Syndrome)</td>
</tr>
<tr>
<td>Web of Science</td>
<td>(body image OR body dissatisfaction OR body integrity OR identity disorder OR self-perception OR self-concept OR self esteem) AND (down syndrome OR trisomy 21)</td>
</tr>
</tbody>
</table>

Source: The authors.

A manual search was also conducted in specific journals of scientific literature that consider the various intellectual difficulties: International Journal of Development Research (IJDR), Disability & Society, Journal of Human Growth and Development (JHGD), Journal of Applied Research in Intellectual Disability (JARID) e Journal of Intellectual Disability Research (JIDR).
STEP 3: STUDY SELECTION

The inclusion criteria were studies that evaluated self-perception and self-concept, based on the perception and concept that children and adolescents with Down Syndrome develop about themselves, published in peer-reviewed journals. Theses, dissertations, and abstracts from scientific events were excluded, as well as studies that extended the research population to children and adolescents with intellectual disability (ID), which may not be associated with DS. Literature reviews and case reports were also excluded. There was no language restriction.

The CCP strategy was used for the inclusion of the studies in this review, being P (population): children and adolescents, C (concept): Self-Perception and Self-Concept, and C (context): individuals with Down Syndrome.

One of the authors did the initial search (R.G.L.N.) in the journals and another author (R.T.F.C.) reviewed the results. A search was also performed in the references of the articles included in this review. The choices made by the reviewers were analyzed by a third and fourth reviewer. A consensus was reached through discussion. After the database searches, duplicate articles were excluded. For this, the Mendeley Reference Manager Ltd. (Mendeley Ltd., Elsevier) was used for this. To determine inclusion, each article was read in full by two reviewers.

STEP 4: CHARTING THE DATA

Two reviewers independently extracted the data and the following variables were collected from the selected articles: authors/year, site, study type, objective, sample/age group, instruments, results, and conclusion. The criteria were additionally reviewed for necessity and completeness by another reviewer prior to extraction. From the data extraction, a synthesis was constructed through thematic analysis, related to the guiding question of this review. The initial coding and analysis was done by two reviewers, who discussed the content of the themes and subthemes, reaching consensus after the second meeting.
STEP 5: COLLATING, SUMMARIZING AND REPORTING THE RESULTS

The selected studies, the distribution of their selection was presented in the form of a flowchart, proposed by PRISMA - check list for systematic reviews. The data are presented in tabular form with the individual results of each study.

2.1 RISK OF BIASE

The Axis - Development of a critical appraisal tool to assess the quality of cross-sectional studies was used to analyze the risk of bias of the selected studies (Downes, Brennan, Williams, Dean, 2016), composed of 20 items to verify the methodologies of cross-sectional studies. The instrument was applied by two researchers. The risk of bias assessment can be found in the table 2.

3 RESULTS

3.1 STUDY SELECTION

The literature survey was conducted in September 2021 from published records indexed in the electronic databases VHL/Lilacs, Cochrane Lybrary, Embase, PubMed/MEDLINE, Scielo, Scopus, and Web of Science. The database search and manual searches identified 2437 articles. With the help of the software Mendeley Reference Manager Ltd. (Mendeley Ltd., Elservier), 358 articles found to be duplicates were excluded. Of the remaining 2079 articles, the reviewers read the titles and abstracts and excluded 2065 studies for not responding to the review questionnaire. Of the 14 articles selected for full-text reading at this stage, seven articles were excluded for: population outside the targeted age range (n=3), case report (n=2), review articles (n=1) and not answering the guiding question (n=1). Thus, seven studies were included.
3.2 SYNTHESIS RESULT

The characteristics of the included studies are presented in figure 2, 6 cross-sectional studies and 1 mixed (qualitative and quantitative). Considering the nature of the guiding question and the two diverse possibilities of answers, the selected researches were conducted in different countries, with variable sample sizes and instruments. Grouping the studies found into categories for better analysis, we established the categories according to the understanding of the aspects of self-perception and self-concept. Thus, the studies were grouped as follows: a) body influence; b) social preferences; c) lifestyles and personal achievement; d) school environment.

The most recent works conducted in Brazil considered the self-perception of DS individuals from the body perspective. In Scotland and in the USA,
considered self-perception as self-acceptance, based on social preferences and self-categorization of individuals with DS. Have investigated self-perception based on life satisfaction. The oldest work, which assesses the self-perception of 63 students with DS, aged eight to 16 years, evaluating three school-related domains: academic competence, physical competence, and social acceptance.

4 DISCUSSION

The results of this systematic review suggest that the body and lifestyles of children and adolescents with Down Syndrome strongly influence the self-concept and self-perception of these individuals.

4.1 BODY SELF-PERCEPTION

The relationship between body self-perception and psychomotor development, as well as between perception and satisfaction with body image were confirmed by this review. The study (Silva, Cotonhoto, Souza, 2020) pointed out that the body self-perception of children with Down Syndrome is related to body and environmental stimuli, linked to psychomotor and cognitive development. On the other hand, the research (Boiani, Maniglia, Kakeshita, Manochio-Pina, 2019) found a relation between perception and body image, besides a discrepancy between anthropometric indexes and satisfaction with the body concept. The study pointed out that 40.74% of the participants were overweight and had fat accumulation in the abdominal region. However, in 26.4% of the male participants, there was a desire to increase body silhouette, and in 52.4% of the female participants, there was a desire to reduce body silhouette. Anthropometric instruments (scale, stadiometer, measuring tape) (Boiani et al, 2019), and the Silhouette Figures Scale were used, validated for the Brazilian population, in addition to the Curve of Cronk and collaborators, designed to interpret the measurements of individuals with DS. It had as sample 27 individuals, aged between five and 18 years, a sample that was also not very significant.
Considering that the satisfactory construction of body image is made from the experience of movements in the world, with its limitations and possibilities, have suggested that the development of a child with Down Syndrome varies according to stimuli received, cultural, social, and environmental influence (Silva et al., 2020). However, it does not follow age patterns. Children of different ages had similar performance in the drawings made in the Body Notion factor of the Psychomotor Battery (PMB), an instrument that evaluates sensory and perceptual aspects.

4.2 WAYS OF LIFE AND PERSONAL FULFILLMENT

The study (Skotko, Levine, Goldstein, 2011) found that 96% of people with DS in the US are happy and satisfied with their lives. The responses showed that there is a relationship between self-esteem and the number of parents living at home, religion, the geographical location in which one lives, and living and health conditions. The majority expressly revealed that they were very satisfied with their own lives and advised parents who were expecting children with DS to love their children, because the family would be happier with the arrival of the children. On the other hand, the participants who declared themselves to be sad were young adults in high school or having just finished it. Replicating Skotko’s research (Wakai, Takahashi, Higashigawa, Ikeda, Yotsumoto, Numabe, 2018) in Japan, found a population of people with Down’s Syndrome with 85% satisfaction with their lives. The difference may have been caused by a cultural difference between the countries, specifically in the relationship between the participants and their parents, family members, and significant others. The authors used the same questionnaire and methodology as in the first study. Besides demonstrating that there is a variation of happiness according to culture, it emphasized the need to compare the results of people with and without Down Syndrome and people without the condition (Wakai et al., 2018).
4.3 SELF-PERCEPTION AND SOCIAL PREFERENCES

It was pointed out that the older they are, the more they are able to identify Down's Syndrome in themselves (Saha, Doran, Osann, Hom, Movsesyan, Rosa, 2014). According to the study, participants see people with typical development as more attractive, smarter, cooler, and more athletic than those with the DS phenotype. It is suggested that there is an association between the quality of a child's self-perception and the stage of development of the child. The younger they are, the more difficult it is to perceive the physical differences between themselves and people with typical development. The researchers draw on previous studies to remind us that it is from a mental age of eight years that children with intellectual disabilities begin to differentiate personas and create complex social patterns. The researchers found preferences of children with Down Syndrome for playing with dolls with typical developmental phenotypes over those with phenotypes similar to theirs. It is concluded that people with Down Syndrome internalize a social stigma and that this should have a direct impact on their quality of life. Thus, it is important to realize the possible relationship between the study (Saha et al., 2014) which focuses on social preferences, and those, that indicate, respectively, a 96% and 85% percentage of happiness and satisfaction in people with Down Syndrome in the United States and Japan.

The self-perceptions of people with Down syndrome regarding their own syndrome was investigated and also found out their preferences in socializing with people without the genetic condition (Deakin, Moore, Jahoda, 2018). The study showed that the amount of participants with Down syndrome who identified with the group of people with typical development was statistically significant. Also significant was the attribution of positive characteristics by both groups of participants for people with typical development. The authors concluded that people with Down syndrome have internal understanding about their own condition. However, the fear that family members and caregivers have of talking about the topic may lead them to misunderstand that the people who support them agree with the social stigma they perceive. It is necessary, then, to bring to family members and professionals who work with people with Down Syndrome
the information that it is the prejudice itself that leads this population to have an ambivalent sense of themselves.

4.4 SELF-PERCEPTION OF CHILDREN AND ADOLESCENTS IN SCHOOL DOMAINS

The self-perceptions of students with DS elaborated was investigated in three school-related areas: physical competence, academic competence, and social acceptance (Begley, 1999). They observed that, in general, the students surveyed presented a positive view of themselves. A fact that draws attention is that of the three areas surveyed, two showed higher scores: physical competence and academic competence, and a lower one for social acceptance. This result suggests that these domains are judged only by personal evaluations, which is not the case with the third item. This is because social acceptance is based on evaluations about the behavior and attitudes of others. This result suggests a need for further studies on the social acceptance of children and adolescents with DS, as stated in the studies (Deakin et al., 2018; Saha et al., 2014).

5 LIMITATIONS AND IMPLICATIONS FOR FUTURE RESEARCH

The included studies were heterogeneous in terms of definitions, methodologies, study population, and instruments used. The wide variation in methods used to assess behavior and the different psychosocial factors studied may make it difficult to compare the results of different studies. Of the seven studies, only two used the same instrument. More consistent use of methodologies and definitions and a stratified analysis would be beneficial to compare the studies and compile them into a meta-analysis. Regarding their satisfaction, biases were found due to limitation in the application of the questionnaires.

6 CONCLUSIONS AND IMPLICATIONS

Results regarding self-perception, self-concept, and social preferences converged in the sense that people with Down Syndrome are aware that they
have the syndrome. However, according to the environment in which they are inserted, they introject the stigma of disability that is applied to them. This opens up a field for research, since there is a conflict between results that show a negative self-perception and results that show happiness and satisfaction with themselves. Regarding body self-perception, this review showed the scarcity of studies focused on Down Syndrome, especially with representative samples. In addition, the subjective nature of the review question, demonstrated the lack of standardization of the instruments used in the studies found. This difficulty suggests the need for further research that considers the subjective aspects of self-perception in this population. However, the research in this review highlights relevant aspects that can guide the development of public policies and social transformation through the inclusion.

ACKNOWLEDGMENT

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REFERENCES


### List of Table

**Figure 2 – Characteristics of the included studies.**

<table>
<thead>
<tr>
<th>Authors/Year</th>
<th>Study location</th>
<th>Type of study</th>
<th>Objective</th>
<th>Participants</th>
<th>Instruments</th>
<th>Results</th>
<th>Conclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Silva, Cotonhoto, Souza. 2020</td>
<td>Brazil</td>
<td>Quantitative and qualitative observational study</td>
<td>To analyze body self-perception self-perception in individuals with DS¹</td>
<td>Children between 7 and 9 years old (n=10)</td>
<td>PMB Body Sense Factor ². Scores: 10 – Satisfactory 15 – Good 20 - Excellent Qualitative evaluation of designs obtained by PMB</td>
<td>PMB below the average of a typical child of the same age (6.7) Children showed the greatest deficits in R-L³ identification, notion of self-image, and the ability to imitate gestures. Children with higher PMB scores had drawings with more body detail</td>
<td>Body self-perception depends on the development of psychomotor skills, and not only on age</td>
</tr>
<tr>
<td>Boiani, Maniglia, Kakeshita, Manochio-Pina. 2019</td>
<td>Brazil</td>
<td>Cross-Sectional Study</td>
<td>To identify the perception and satisfaction of body image body image of young people with DS</td>
<td>Persons with DS between the ages of 5 and 18. N=27</td>
<td>Anthropometric Assessment Silhouette Figures Scale</td>
<td>Anthropometric measurements: 11% underweight 48% underweight 40.74 overweight The current BMI was higher than the desired BMI, with a statistically statistically significant difference in both genders genders and in the group in general (p&lt; 0.05).</td>
<td>Dissatisfaction with body size was observed, associated with increased CC5. There was agreement between perception and current body image, but dissatisfaction with the image.</td>
</tr>
<tr>
<td>Wakai, Takahashi, Higashigawa, Ikeda, Yotsumoto, Numabe. 2018</td>
<td>Japan</td>
<td>Cross-Sectional Study</td>
<td>Investigating self-perception of life and life satisfaction among adolescents</td>
<td>Persons with DS aged 12 years and older. n=80</td>
<td>Closed-Ended Questionnaire by Stokto and collaborators</td>
<td>97% are happy 94% like who they are 69% find it easy to make friends 68% believe they help people 61% like the way they look</td>
<td>The satisfaction rate of people with DS about life in the United States is higher than in Japan. Figures show that people satisfied with life in the USA is</td>
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<tr>
<td>Study</td>
<td>Location</td>
<td>Design</td>
<td>Focus</td>
<td>Participants</td>
<td>Methods</td>
<td>Findings</td>
<td>Notes</td>
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<tr>
<td>Deakin, Moore, Jahoda. 2018</td>
<td>Scotland</td>
<td>Cross-sectional study</td>
<td>To investigate the self-perception of children and youth with DS</td>
<td>Persons with DS between 8 and 17 years old, n=28</td>
<td>Structured non-verbal free play tasks: (1) Social Partner Preference, (2) Classification and Self-Categorization and (3) Attribution</td>
<td>82% of people with DS prefer to be friends with people with typical development. 22 out of 27 participants were aware that they had DS. 33% reported receiving name-calling.</td>
<td>Children with DS perceive their condition and the social aspects related to it at an early age.</td>
</tr>
<tr>
<td>Saha, Doran, Osann, Hom, Movsesyan, Rosa, et al. 2014</td>
<td>Washington (USA)</td>
<td>Cross-sectional study</td>
<td>To evaluate the body self-perception of children and youth with DS</td>
<td>Children and adolescents with DS aged 4 to 17 years, n=54</td>
<td>Sociodemographic questionnaire; Script game with dolls and open interview</td>
<td>Children with DS attributed: 71% - positive qualities to dolls with typical appearance 72% - more friends for dolls with TD 69% - a good person to dolls with TD 71% - better at sports for dolls with TD 52% - more intelligent for TD dolls 52% of the participants chose the doll with TD as the one who looked the most like them</td>
<td>Participants see individuals with TD as more attractive, smarter, nicer, and more athletic than individuals with phenotypic characteristics of DS</td>
</tr>
<tr>
<td>Skotko, Levine, Goldstein. 2011</td>
<td>Boston (USA)</td>
<td>Cross-sectional study</td>
<td>Investigate the life satisfaction of People with Down syndrome</td>
<td>Likert-scale questions - Questionnaire produced</td>
<td>99% happy with their life 97% like who they are 96% like the way they look</td>
<td>People with DS in the USA live happy and fulfilling lives</td>
<td></td>
</tr>
<tr>
<td>Begley. 1999</td>
<td>UK (London)</td>
<td>Cross-sectional study</td>
<td>To examine the self-perceptions of students with DS in three school-related areas</td>
<td>n = 64 divided into 3 groups 8-10 years (n=18) 11 to 13 years (n=19) 14 to 16 years (n=27)</td>
<td>Pictorial Scale of Perceived Competence and Acceptance (PSPCA) School Situations Grid (SSG)</td>
<td>PSPCA: Scores 1-4 3.42 - S 3.52 - Ph 3.47 - AC SSG: Scores 1-3 2.46 - AC 2.49 - Ph 2.37 – S In the age comparison PSPCA 8 to 10 AC - 3.47 Ph - 3.52 S - 3.45 SSG 8 to 10 AC -2.37 Ph - 2.41 S - 2.22 PSPCA 11 to 13 years AC - 3.39 Ph - 3.58 S - 3.30</td>
<td>Regardless of the domain of self-perception, students with DS have a positive view of themselves. In general, children and adolescents with DS have lower scores for social acceptance</td>
</tr>
</tbody>
</table>
Table 2 – Assessment of the risk of bias in the included studies based on the Critical appraisal tool to assess the quality of cross-sectional studies (AXIS check-list).

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<tbody>
<tr>
<td>1 Were the study objectives clear?</td>
<td>✔</td>
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<td>2 Was the study design appropriate for the stated objectives?</td>
<td>✔</td>
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<td>3 Was the sample size justified?</td>
<td>✔</td>
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<tr>
<td>4 Was the target/reference population clearly defined?</td>
<td>✔</td>
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<tr>
<td>5 Was the sampling frame drawn from an appropriate population base to closely represent the target/reference population under investigation?</td>
<td>✔</td>
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<tr>
<td>6 Did the selection process likely select individuals representative of the target-reference population under investigation?</td>
<td>✔</td>
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<td>7 Were steps taken to address and categorize non-responders?</td>
<td>✔</td>
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<tr>
<td>8 Were the risk factor and outcome variables appropriate to the study objectives?</td>
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<td>9 Were risk factor and outcome variables correctly assessed using instruments/measures that had been previously tested or published?</td>
<td>✔</td>
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<td>10 Is it clear what was used to determine statistical significance and/or precision?</td>
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<td>11</td>
<td>Are the methods (including statistical methods) described sufficiently to allow for their repetition?</td>
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<td>12</td>
<td>Are the basic data adequately described?</td>
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<td>13</td>
<td>Does the response rate raise concerns about non-response bias?</td>
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<td>14</td>
<td>If appropriate, was information described about those who did not respond?</td>
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<td>15</td>
<td>If appropriate, was information about non-responders described?</td>
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<td>16</td>
<td>Were the results internally consistent?</td>
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<td>17</td>
<td>Were the authors’ discussions and conclusions justified by the results?</td>
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<td>18</td>
<td>Were the limitations of the study discussed?</td>
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<td>19</td>
<td>Were there any funding sources or conflicts of interest that might affect the authors’ interpretation of the results?</td>
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<td>20</td>
<td>Was ethical approval or consent obtained from the participants?</td>
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Source: The authors

(re), No; (yellow), Don’t know/comment; (green), Yes.