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INPLASY

Evaluation of quality of life questionnaires in children and young adults with cleft lip and/or palate and/or jaw: protocol for a scoping review

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ADMINISTRATIVE INFORMATION

Support - Department of Dentistry, Orthodontics and craniofacial biology.

Review Stage at time of this submission - Formal screening of search results against eligibility criteria.

Conflicts of interest - None declared.

INPLASY registration number: INPLASY202390047

Amendments - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 14 September 2023 and was last updated on 14 September 2023.

INTRODUCTION

Review question / Objective Which (non)validated questionnaires are used in scientific literature on assessing the quality of life (QoL) of young individuals with a cleft lip and/or cleft palate and/or cleft jaw and which quality of life domains are used in those questionnaires?
P: Patients with non-syndromic uni- or bilateral cleft in lip and/or palate and/or jaw; of all ages; male or female.; I: Patients have received a questionnaire on their perceived QoL before/after a treatment.; C: -; O: The questions in the questionnaire and their associated domains.

Rationale We aim to delineate the breadth and depth of QoL domains encompassed by these measurement tools, identify potential gaps, and offer insights for the development of more comprehensive and standardized assessment instruments. Furthermore, this review endeavors to contribute to the scientific community by fostering a deeper understanding of the impact of orofacial clefts on QoL and endorsing evidence-based strategies for optimizing patient care and treatment outcomes.

Condition being studied Cleft patients need yearly functional and esthetic treatments of a multidisciplinary team of orthodontists, maxillofacial surgeons, plastic surgeons, ENT specialists, speech therapists and pediatricians, starting from a young age. The physical, psychological, and socio-emotional implications associated with cleft lip and palate profoundly affect the overall quality of life (QoL). It is a subject born from the growing interest of medical researchers in the effects of their treatment on the overall wellbeing of their patients themselves (not parents, not clinicians). More and more practitioners in the medical field like to share questionnaires with patients to evaluate the influence of the treatment on not only the dimension of cure or improvement of their disease but also on the dimension of well-being, the health-related quality of life (HRQoL). Within the realm of cleft lip and palate research, subjective measures such as questionnaires, patient-reported outcome measures (PROMs), and patient-reported experience measures (PREs) have been widely employed to evaluate QoL. These instruments provide a valuable means of capturing the perspectives and experiences of patients directly, without the interpretation of a clinician, enabling a comprehensive assessment of QoL across diverse domains. Nonetheless, the domains of QoL encompassed by these measures exhibit considerable heterogeneity across studies, leading to challenges in synthesizing findings and establishing a standardized, age independent and disease specific approach that can be annually distributed to QoL assessment in cleft patients. Consequently, conducting a scoping review that systematically explores the QoL domains evaluated through questionnaires, PROMs, and PREs administered to individuals with cleft lip and palate assumes utmost significance.

METHODS

Search strategy A PRISMA Scoping Review literature search developed by a medical librarian was performed in electronic databases (PubMed, Cochrane, Embase, PsycINFO, CINAHL, Web of Science and Google Scholar) to identify relevant publications from the inception of the databases until 21 February 2023. There are no restrictions on publication date or language.

(("Cleft Palate"[Mesh] OR "Cleft Lip"[Mesh] OR "Alveolar Cleft"[tiab:~3] OR "Alveolar Clefts"[tiab:~3] "Cleft lip"[tiab:~3] OR "cleft lips"[tiab:~3] OR "cleft palate"[tiab:~3] OR "cleft palates"[tiab:~3] OR orofacial cleft*[tiab] OR oro-facial cleft*[tiab] OR "cleft alveolus"[tiab] OR harelip*[tiab] OR hare-lip*[tiab] OR oral cleft*[tiab] OR dental cleft*[tiab]) AND (("Quality of Life"[Mesh] OR "QOL"[tiab] OR "quality of life"[tiab] OR "OHRQOL"[tiab] OR life qualit*[tiab] OR living qualit*[tiab] OR "quality of living"[tiab] OR "Activities of Daily Living"[Mesh] OR "activities of daily living"[tiab] OR "activity of daily living"[tiab] OR "activities of daily life"[tiab] OR "activity of daily life"[tiab] OR daily living activit*[tiab] OR daily life activit*[tiab] OR "adl"[tiab] OR "chronic limitation of activity"[tiab] OR self care*[tiab] OR "Health Status"[Mesh] OR "health status"[tiab] OR "level of health"[tiab] OR health level*[tiab] OR "hrql"[tiab] OR "hrqol"[tiab]) OR ("Pain"[Mesh] OR pain*[tiab] OR ache*[tiab] OR "Pain Measurement"[Mesh] OR "Hyperalgesia"[Mesh] OR hyperalgesi*[tiab] OR allodyni*[tiab] OR "Pain Perception"[Mesh] OR nocicepti*[tiab] OR vas[tiab] OR visual analog scale*[tiab]) OR ("self-esteem"[tiab] OR "patient’s perspective"[tiab] OR Patient Participation[Mesh] OR consumer participation[Mesh] OR Professional-Patient Relations[Mesh] OR Patient-Centered Care[Mesh] OR Patient Preference[Mesh] OR Patient Satisfaction[Majr] OR Patient Education as Topic[Mesh] OR Attitude to Health[Mesh] OR Attitude to Death[Mesh] OR Patient Acceptance of Health Care[Mesh] OR Health Knowledge, Attitudes, Practice[Mesh] OR Focus Groups[Mesh] OR Quality of Life[Majr] OR Self Care[mh:noexp] OR Self Concept[Mesh] OR Self-examination[Mesh] OR Cooperative Behavior[Mesh] OR Adaptation, Psychological[Mesh] OR Decision Support Techniques[Mesh] OR Self-Help Groups[Mesh] OR Community Networks[Mesh] OR Emotions[Mesh] OR Consumer Satisfaction[Mesh] OR Needs Assessment[Mesh] OR Personal Autonomy[Mesh] OR Patient Advocacy[Mesh] OR Life Change Events[Mesh]) OR (patient perspective*[tiab] OR patient's perspective*[tiab] OR patient desire*[tiab] OR patient's desire*[tiab] OR patient view*[tiab] OR patient's view*[tiab] OR patient expression*[tiab] OR patient's expression*[tiab] OR patient attitude*[tiab] OR patient's attitude*[tiab] OR patient involvement*[tiab] OR patient's involvement*[tiab] OR patient decision*[tiab] OR patient's decision*[tiab] OR patient activation[tiab] OR patient's activation[tiab] OR patients activation[tiab] OR patient empowerment[tiab] OR patient participation[tiab] OR patient's participation[tiab] OR patients participation[tiab] OR patient collaboration[tiab] OR patient's collaboration[tiab] OR patients collaboration[tiab] OR expert patient*[tiab] OR consumer participation[tiab] OR consumer perspective[tiab] OR consumers perspective[tiab] OR consumer's perspective[tiab] OR consumer involvement[tiab] OR patient-focused[tiab] OR patient-centred[tiab] OR patient-centered[tiab] OR patient needs[tiab] OR self-management[ti] OR self-perception[tiab]) OR Patients[Majr] AND (Communication[MeSH Terms] OR Decision Making[Mesh]) OR (self-esteem[tiab] OR "Self Concept"[Mesh]) OR (Self-perception[tiab]) OR (facial aesthetics[tiab] OR facial esthetics[tiab] OR "Esthetics"[Mesh] OR "Esthetics, Dental"[Mesh])) AND ("Surveys and Questionnaires"[Mesh] OR questionnaire*[tiab] OR survey*[tiab] OR qualitat*[tiab] OR instrument*[tiab] OR measure*[tiab]).

Participant or population Patients with non-syndromic uni- or bilateral cleft in lip and/or palate and/or jaw; of all ages; male or female.

Intervention Listing of all QoL domains used to assess QoL of cleft patients via questionnaires, PROMs and PREs.

Comparator None.

Study designs to be included (Randomized) controlled trials, prospective studies, cohort studies, (systematic) review.

Eligibility criteria Included articles are about studies with people diagnosed with a lip and/or palatal and/or alveolar cleft (combined with craniofacial deformities) evaluated by a child- or parent-completed QoL questionnaire, PROM or PRE. Exclusion criteria are: only abstract published; development or validation of questionnaires to any other language than English; not original research articles (e.g. editorials, case reports); an unstructured interview in open style; investigation of primarily non QoL outcomes; studies that used unvalidated or modified questionnaires but lack disclosure on the domains or the stated questions.

Information sources Electronic searches on PubMed, Cochrane, Embase, PsycINFO, CINAHL, Web of Science and Google Scholar. authors were contacted for further information and asked for article if not otherwise accesible.

Main outcome(s) QoL questionnaires and QoL (sub)domains are selected as the main (primary) outcome.

Additional outcome(s) Additional outcomes are considered to be all recommended domains and questions that are not part of consisting QoL questionnaires but were additionally asked by researchers or suggested to include in future studies and questionnaires.

Data management A PRISMA Scoping Review literature search developed by a medical librarian was performed in electronic databases (PubMed, Cochrane, Embase, PsycINFO, CINAHL, Web of Science and Google Scholar) to identify relevant publications from the inception of the databases until 21 February 2023. Screening on title and abstract was independently executed by two researchers (IM and MK). A third researcher was involved in case of any disagreement. Rayyan will be used for reference management.

Quality assessment / Risk of bias analysis The goal of the review is to specify the type of OHRQoL questionnaires in cleft patients, hence no risk of bias analysis was used used to identify these. in- and exclusion criteria were used. Quality assessment is executed independently by two reviewers. Any discrepancies between the two reviewers is resolved by consensus discussion with the third reviewer.

Strategy of data synthesis A structured 5-step pathway for data extraction was developed, guided by the authors' expertise, to extract the QoL domains from the included studies. Given the scoping nature of the review, the objective was to summarize the data based on key findings in a descriptive manner. Extracted data will include study characteristics, details of the utilized questionnaires, PROMs, and PREs employed, domains of QoL assessed and sample characteristics. Additionaly, the extracted data will be analyzed using thematic analysis to identify prevalent QoL domains and to explore variations among studies. The results will be displayed in tables to enhance the accessibility of the scoping review.

Subgroup analysis If the necessary data are available, analysis will be done on i.e. gender, age groups, demographic information.

Sensitivity analysis None reported.

Language restriction There is no language restriction.

Country(ies) involved The Netherlands.

Keywords Quality of Life, Oral Health related Quality of Life, PROM, PRE, questionnaire, cleft, cleft lip, cleft palate, cleft jaw.

Dissemination plans The results of the scoping review will be published in an international, peer-reviewed journal, and will also be presented in (inter)national conferences.

Contributions of each author

Author 1 - Irena Middeljans - Designing the review, data collection, data management, analysis of data, interpretation of data, writing the protocol and review.
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