BMC Oral Health

RESEARCH

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The burden and care of orofacial cleft in Rwanda: a scoping review

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Abstract

Background Orofacial clefts (OFCs) are among the most common congenital anomalies accounting for over 4.6 million cases globally. In many developing nations, OFCs are associated with significant morbidity and a heightened risk of infant mortality due to barriers to accessing multidisciplinary care. This scoping review aims to identify knowledge gaps, establish research agendas, and inform decision-making for policy redirection in Rwanda regarding OFCs.

Methods The design and reportage of this scoping review were based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews. Following the search of eleven electronic databases, all retrieved articles were imported into the Rayyan web application where deduplication of literature was done. One hundred and fourteen articles were obtained from the literature search. After screening and deduplication, six articles were included in the scoping review for data charting, collation, and summarization.

Results Rwanda faces a substantial burden of OFCs, with prevalence rates ranging from 12.1 to 34.2% across its provinces. The scarcity of specialists who treat OFCs highlights a significant disparity in healthcare access. The prevalence of OFCs varies among demographics and age groups, with a higher incidence in males compared to females. This review also addresses the clinical management of OFCs in Rwanda, highlighting a low retention rate among patients receiving care.

Conclusion This review highlights the need for targeted interventions in OFC care in Rwanda, including the early detection of associated anomalies, enhanced prenatal management, and improved access to specialized treatment facilities, particularly for patients with concomitant malformations. Policymakers and stakeholders must implement strategies to increase the number of specialists supporting individuals with OFCs and ensure high retention rates in OFC care. Further, OFC-related studies with representative sample sizes and advanced research designs are required to address the information gap and better inform Rwandan health policy.

Keywords Orofacial cleft, Rwanda, Scoping review, Public health

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Background

Orofacial cleft (OFC) is the most common congenital anomaly of the head and neck, with a global prevalence estimate of 4.6 million cases [1]. Orofacial cleft is characterized by facial deformation and structural gaps in the craniofacial complex causing serious aesthetic and functional challenges [2–5]. Unfortunately, due to serious aesthetic and functional challenges associated with OFC, OFC patients often suffer from societal stigma, speech and feeding problems, middle ear infection and increased risk of caries [2–5].

While the global prevalence of OFC averages 1 in 700 live births, this prevalence significantly varies across different geographic regions and ethnic groups, with reported rates ranging from 1 in 2,500 among Africans to 1 in 500 among Asian and Amerindian populations [6, 7]. In Nigeria, which is the most populous African country, the prevalence of OFCs is 0.3 cases per 1,000 live births [7, 8]. In Kenya, another African country, a significantly higher prevalence of 1.65 cases per 1,000 live births was observed among its populations [7, 8]. However, in some other African countries like Rwanda, there is a paucity of epidemiological information about OFCs leaving information sources to the mass media [8].

Oro-facial clefts may occur as isolated cases or as part of an underlying syndrome [6]. Isolated cases of orofacial clefts have been linked to various risk factors, including maternal substance use, infections during pregnancy, prenatal nutritional deficiencies, and the use of herbal medications, particularly in certain regions of Africa [6].

Cultural beliefs and superstitions, often associated with witchcraft, bad omens, and punishment for parental misdeeds, frequently entangle OFCs in Africa [9]. These beliefs create stigma, imposing significant psychological and social burdens on affected families. Misconceptions about OFCs lead to discrimination and social isolation among sufferers, hindering access to education, employment, and social opportunities, thereby perpetuating poverty and marginalization [10, 11]. Understanding these health frames is crucial due to the unique social construction of health in Africa [12].

Despite a well-organized health system and almost 100% community health insurance coverage, up to 500 children are born with OFC annually in Rwanda and a tenth of these newborns may die before they reach the age of one year [8]. While early surgical correction is advocated, there is still a worldwide backlog of untreated patients with the attendant consequences of increased OFC patient morbidity and mortality [2]. This situation is partly due to a severe shortage of a specialised multidisciplinary workforce [13]. It is noteworthy that the management of OFCs in resource-limited countries of Africa has made considerable strides over the past two decades due to interventions by international organizations [8]. However, several challenges hindering cleft care in Africa persist [7, 8]. These challenges include African perceptions, adult presentations, a lack of awareness regarding treatability, specialist availability, funding for non-surgical aspects of care, and patient and hospital-related obstacles [7, 8]. Given the paucity of scientific information on OFC care in Rwanda, this scoping review aims to compile all empirical evidence concerning the burden and care of OFCs in the country. This study seeks to identify knowledge gaps, establish research agendas, and inform decision-making for policy redirection by the Rwandan government regarding cleft care.

Methods

Research design

The design of this scoping review was based on the methodological frameworks proposed by Arksey and O'Malley [14], and Levac et al. [15]. Additionally, the review was reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist [16].

Identification of the research question

The PCC (P – Population, C – Concept, and C – Context) framework was used to develop the research question of this scoping review [17]. Based on this framework, the population of focus was individuals (of all age groups) with OFC, the concepts were disease burden and care, and the context was Rwanda. Hence, the research question for this review reads as follows: "What are the existing evidence on the burden and care of OFCs in Rwanda?".

Identification of relevant literature

Twelve electronic databases (SCOPUS, PubMed, APA PsycTests, APA PsycArticles, APA PsycINFO, AMED – The Allied and Complementary Medicine Database, CINAHL Ultimate, Dentistry & Oral Sciences Source, Child Development & Adolescent Studies, Psychology and Behavioral Sciences Collection, SPORTDiscus with Full Text, and Google Scholar) were searched to retrieve all literature relevant to the scoping review question.

This search, aided by Boolean operators ("AND" and "OR") and truncations ("*"), was conducted using relevant search terms which were obtained from the Medical Subject Heading Dictionary and Thesaurus: 'cleft', 'oral', 'dental', 'mouth', 'lip', 'labial', 'palate', 'orofacial', 'facial', 'face' and 'Rwanda'. Prior to conducting the search, each of the search terms (as well as their truncated forms e.g. palat*) was test-ran on the selected databases to examine their sensitivities and appropriateness. Based on the outcomes of this test-run, the search strings were developed. The search strings used for the literature search strategy are depicted in Tables S1 to S4 (Supplementary File).

The search was conducted on 16 January 2024, and updated on June 10, 2024, and all literature obtained from the database searches were retrieved, except for those obtained from Google Scholar where only the first 100 hits were retrieved. Only the first 100 hits obtained from Google Scholar were retrieved because research evidence has proven and recommended that only the first 100 hits obtained from a search on grey literature databases (e.g., Google Scholar) are relevant to such search [18, 19].

Literature deduplication, screening and selection

All retrieved literature were imported into the Rayyan web application where deduplication was done [20]. Thereafter, all the deduplicated literature were screened by two independent reviewers (JM [a dental therapist and a dental public health practitioner] and IEH [a dental therapist]) who were guided by a set of inclusion criteria in a two-step process. The first stage of the screening involved the title and abstract screening to exclude literature that were not relevant to the review while the second stage (Table S5; Supplementary file) involved the full-text screening of all literature included during the first stage of screening. In situations where there were conflicts in the decisions of the two independent reviewers (JM and IEH), a third reviewer (KKK [a dental surgeon and dental public health practitioner]) was invited to resolve the conflicts. Only the literature that fulfilled all the inclusion criteria of this scoping review was included and subjected to data extraction. Below are the inclusion and exclusion criteria that guided the literature screening and selection processes:

Inclusion criteria

1. Literature reporting empirical studies on the burden and care of orofacial cleft in Rwanda (e.g. original research articles, short reports, technical reports, policy briefs).
2. Grey literature and peer-reviewed journal literature (excluding abstracts) whose full texts are accessible.
3. Literature published in English.

Exclusion criteria

1. Literature reporting non-empirical studies on the burden and care of orofacial cleft in Rwanda (e.g. systematic reviews, scoping reviews, bibliometric reviews, letters, editorials, commentaries).
2. Literature reporting empirical studies on the burden and care of orofacial cleft concerning a population outside Rwanda.

Data extraction, collation, and summarization

From the included literature, we extracted data concerning the author names, year of study, journal name, study design, study objectives, study setting, provincial coverage, sample size, sample characteristics, study instrument, study limitations, and relevant findings, using a bespoke data extraction sheet. The data extraction sheet was developed through a review of existing scoping reviews [21, 22] and robust discussions among team members. The extracted data were thereafter collated, summarized, and presented in texts and a table. Two reviewers (JM and KKK) conducted the data extraction, collation, summarization. However, in all cases of conflict in the data, a third reviewer (JA [a medical sociologist and research methodologist]) was consulted to resolve such conflicts. Notably, before the data extraction, collation, and summarization, the reviewers met to pilot the process using one of the included articles. Narrative synthesis approach was used for the collation, summarization, and presentation of the extracted data. The summarized data are presented using texts and tables.

Quality appraisal

All the included literature underwent quality appraisal using the 2018 version of the Mixed Methods Appraisal Tool (MMAT) [22].

Two reviewers, JA [a medical sociologist and research methodologist] and KKK, conducted the appraisal. The approach used by the reviewers was adapted from the study by Adegbile et al. [23]. For each question in the MMAT, the responses were "I can't tell", "No", and "Yes". In the quality appraisal process, the reviewers awarded zero point for a response of "No", 0.5 point for a response of "I can't tell", and one point for a response of "Yes". The minimum point that an appraised literature could get was zero while the maximum points was seven points. Any appraised literature with a cumulative point of 3/7 or below was considered to have "below average" quality, any literature with a cumulative point of 3.5/7 was considered to have "average" quality, and any literature with a cumulative point of 4/7 or above was considered to have "above average" quality (Tables S6 and S7; Supplementary File).

Results

Literature search, deduplication, screening and selection outcomes

The search yielded one hundred and fifteen literatures. Twenty literatures were found to be duplicate copies and were deleted. The remaining 95 pieces of literatures were subjected to a two-stage screening process. All the literatures considered for full text screening were accessible. After screening, only 6 peer-reviewed journal articles were found eligible and were thus included in the scoping

review (Fig. 1). However, no grey literature was found eligible for inclusion in the scoping review.

Study design

All the reviewed articles were cross-sectional studies [8, 24–28] except for one which was on a cohort study [25] (Table 1).

Provincial coverage

Out of the six reviewed articles, five reported empirical findings [8, 23–26] on OFCs in at least one Rwandan province. Out of these five articles, only one [8] reported such findings on all the provinces in Rwanda. Two articles reported on the Northern province [8, 24] four articles reported on the Eastern Province [8, 25–27], one

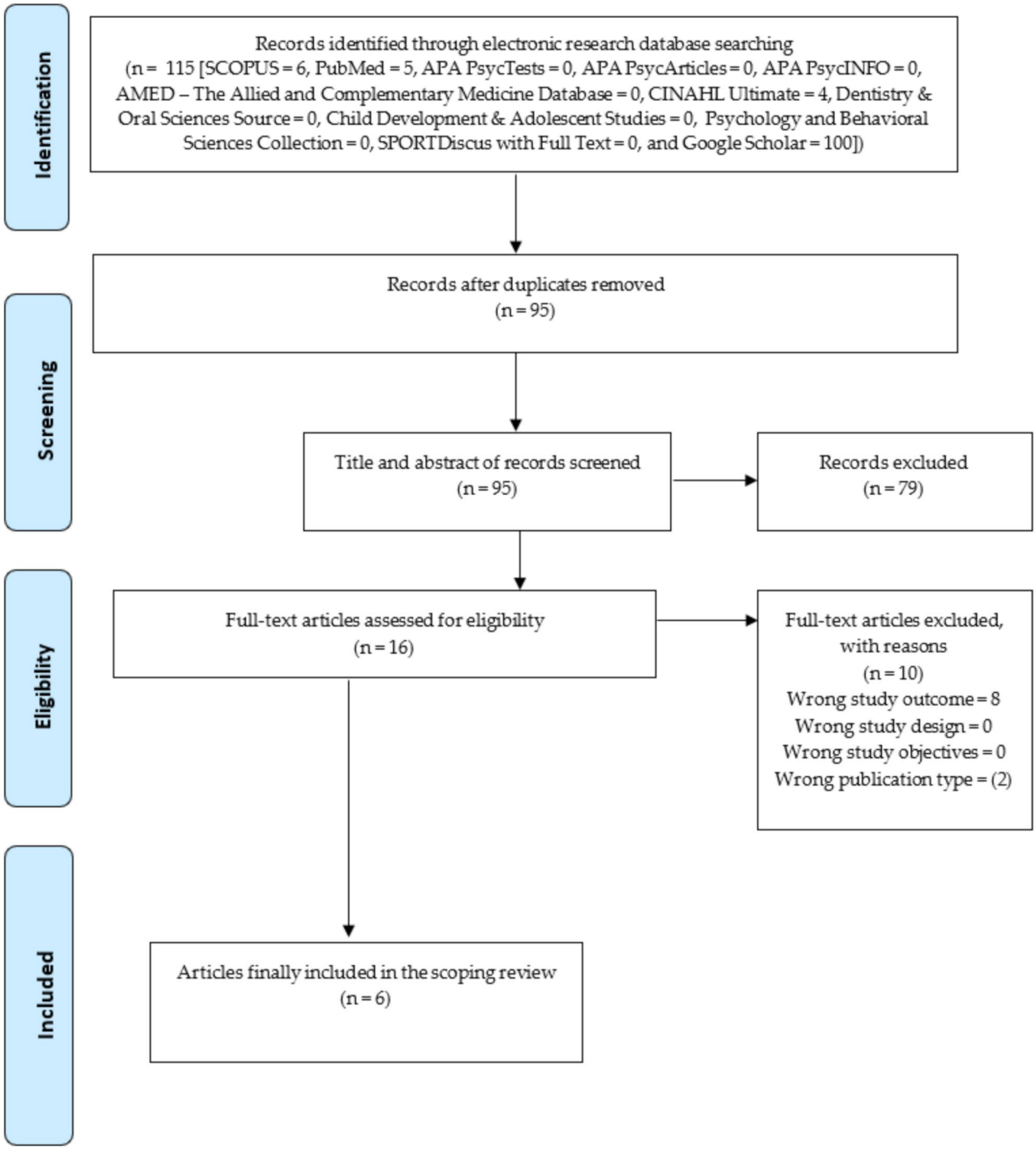

Fig. 1 PRISMA flow chart

Table 1 Characteristics of the included articles

No.	Author (Year)	Journal Name	Study Design	Setting	Provincial Coverage	Sample Size	Sample Characteristics	Study Instrument
1	Maine et al., 2017 [24]	JAMA Surgery	Cross-sectional study	Community-based	Burera District, Northern Province	617 households; 2165 individuals	67.2% were aged 5 to 50 years. 43.8% were males. 80.3% were married.	Survey tool; specificity not stated.
2	Bayitondere et al., 2018 [25]	BMC Pediatrics	Retrospective cohort study	Hospital-based	Kayonza District, Eastern Province	228 children	57.9% were females. 39.5% were 1–11 years old. 70.6% were born pre-term.	Questionnaire
3	Munabi et al., 2019 [26]	Journal of Surgical Education	Cross-sectional study	Hospital-based	Rwinkwavu District, Eastern Province	5 general surgery resident doctors	No biodata presented.	Questionnaire
4	Mumena et al., 2020 [8]	Rwanda Medical Journal	Cross-sectional study	Hospital-based	All provinces in Rwanda	339 operated orofacial cleft patients	100% were aged 0–65 years, of which 88.2% were below 2 years of age. 50.4% were males.	Data collection form
5	Munabi et al., 2020 [27]	Journal of Surgical Education	Cross-sectional study	Hospital-based	Southern, Eastern, and Kigali provinces	6 general surgeons who were participants in a short-term training rotation in plastic surgery	All worked in government hospitals at the time of data collection. No biodata presented.	Questionnaire
6	Belachew et al., 2023 [28]	Global Pediatrics	Cross-sectional study	Organization-based	East Africa	85,544 individuals with orofacial cleft in East Africa (of which 2,371 are in Rwanda)	No biodata specifically presented on individuals with orofacial cleft in Rwanda	Not stated/applicable.

article reported on the Western Province [8], and two articles each reported on the Southern Province [8, 27] and the Kigali Province [8, 27] (Table 1).

Study setting

One of the reviewed articles was on a community-based study [24], four were on hospital-based studies [8, 25–27] and one was on an organization-based study [28] (Table 1).

Study population

Four articles documented the age distribution of their study subjects. One article was a report on both child and adult subjects [24]; one article was on child subjects only [25], one article was on adult subjects only [27]; and one article was predominantly on child subjects (in the article, the upper age limit of the study subjects was not specified; hence, it could not be ascertained if adults were included) [28] (Table 1). One article was a report on community dwellers [24], three articles were on patients [8, 25, 28], and two articles were on healthcare professionals [26, 27] (Table 1).

Epidemiological burden of orofacial cleft cases

Only one article ranked the epidemiological burden of OFC cases in Rwanda with respect to other countries in the East African Community [28]. In the article, Rwanda was ranked, out of fourteen East African countries, to have the eighth highest burden of OFCs-per-country in East Africa. However, the article did not report the national/provincial prevalence of OFC in Rwanda (Tables 1 and 2).

Two articles reported the prevalence of OFCs in Rwanda, and only two districts were identified in those articles. The prevalence of cleft lip/palate was 0% in Burera District (Northern Province of Rwanda) [24] and the prevalence of cleft lip was 1.9% (4/210) in Kayonza District (Eastern Province of Rwanda) [25] (Tables 1 and 2).

Two articles specifically reported the distribution of OFCs in Rwanda in terms of gender, age, disease pattern, and/or geographical location [8, 28]. According to one of these two articles, the male-female ratios of OFC, cleft lip, cleft palate, and cleft lip and palate were 1.02:1, 1.05:1, 1:1.03, and 1:1.8, respectively [8]. Only one article reported the distribution of OFCs with respect to disease patterns. In the article, it was identified that 2371 OFC cases were in Rwanda, of which 62.34%, 27.16%, and 10.5% were cases of cleft lip and palate, cleft lip, and cleft palate, respectively [28] (Tables 1 and 2).

Only one article reported the distribution of OFCs with respect to geographical location. At the provincial level, the prevalence rates of OFCs in the Eastern, Western, Northern, Southern, and Kigali Provinces

Table 2 Summary of findings obtained from the included articles

No.	Author (Year)	Objectives	Findings on orofacial cleft	Limitations of the study
1	Maine et al., 2017 [24]	To determine the prevalence rates of surgical conditions in the District of Burera, Northern Province, Rwanda	The prevalence of cleft lip/palate was 0%	The study only investigated one district. The study only investigated one country. Only 72% of all eligible participants were examined.
2	Bayitondere et al., 2018 [25]	To assess retention and factors influencing retention in care among Paediatric Development Clinic (PDC) patients at 12-month post-referral to the PDC in rural Kayonza District, Rwanda	The prevalence of cleft lip was 1.9% (4/210). Having a cleft lip/palate is associated with lower retention of care in PDC patients.	Missing (incomplete) data. The study was a pilot study; hence, its findings were not generalizable.
3	Munabi et al., 2019 [26]	To assess the efficacy of a three-week surgical training rotation in teaching general surgery resident doctors in Rwanda on plastic surgery skills	- Only 60% (3/5) of the participants have participated in cleft palate repair. - The participants, on average, reported significant improvement in their comfort and confidence in the repairs of unilateral cleft lip (<0.05), bilateral cleft lip (<0.05), and cleft palate (<0.01).	Recall bias.
4	Mumena et al., 2020 [8]	To determine the frequency and epidemiological distribution of orofacial clefts in Rwanda	The male-female ratios of orofacial cleft, cleft lip, cleft palate, and cleft lip and palate were 1.02:1, 1.05:1, 1:1.03, and 1:1.8, respectively. At the provincial level, the Eastern Province had the highest rate (34.2%) of orofacial cleft. At district level, Gasabo had the highest rate (47.6%) of orofacial cleft.	Missing (incomplete) data.
5	Munabi et al., 2020 [27]	To investigate the long-term impact of a short-term training rotation in plastic surgery among practicing general surgeons in Rwanda who have participated in such a program.	- 83.3% (5/6) of the participants frequently performed cleft lip repair during their short-term training rotation in plastic surgery. - 83.3% (5/6) of the participants frequently performed cleft palate repair during their short-term training rotation in plastic surgery. - None of the participants perform cleft lip or cleft palate in their current surgical practices	This study only focused on those who just recently (0–18 months) graduated from a general surgery residency program. This study did not investigate the practice environment of the participating general surgeons to explore factors that might have limited opportunities for performing plastic surgeries by the participants.
6	Belachew et al., 2023 [28]	To evaluate the clinical profile of individuals with orofacial cleft that were operated at Smile Train's partner hospitals in East Africa.	- Rwanda had the eighth-highest prevalence of orofacial cleft, out of 14 East African countries. - 2371 orofacial cleft cases were in Rwanda, of which 62.34%, 27.16%, and 10.5% were cases of cleft lip and palate, cleft lip, and cleft palate, respectively.	The study did not investigate the post-operative outcomes of the study participants.

were 34.2%, 12.1%, 14.5%, 21.3%, and 17.9%, respectively [8]. At the district level, Bugesera was the district in the Eastern Province with the highest rate (38.8%) of OFCs [8]. However, for the Western, Northern, Southern, and Kigali Provinces, Ngororero (26.9%), Musanze (34.7%), Kamonyi and Muhanga (19.4% each), and Gasabo (47.6%) were the districts with the highest rates of OFCs, respectively [8] (Tables 1 and 2).

Care of persons with OFCs

Three articles reported relevant findings pertaining to the clinical care of OFCs in Rwanda [25–27]. Only one article reported such findings concerning patients [25] while two articles [26, 27] reported such findings concerning healthcare professionals. One article [25] reported that having a cleft lip/palate was found to be associated with lower retention (or high dropout) of OFC patients receiving clinical care at a Paediatric Development Centre in Kayonza District [25].

In one of the articles [27], it was reported that 83.3% (5/6) of a group of general surgeons who were participants of a short-term training rotation in plastic surgery frequently performed cleft lip repair during their short-term training rotation in plastic surgery. However, none of them performed cleft lip or cleft palate in their current surgical practices [27].

In one of the articles [26], it was reported that only 60% (3/5) of a group of general surgery resident doctors in Rwanda have participated in cleft palate repair [26]. These resident doctors, on average, were also found to have significantly improved their level of confidence to perform repairs of unilateral cleft lip, bilateral cleft lip, and cleft palate, due to their participation in previous surgical repairs [26].

Quality appraisal outcomes

All the included articles were found to have above average quality, after being appraised using the MMAT (Tables S6 and S7; Supplementary file).

Discussion

Rwanda faces a high burden of cleft lips and palate (OFCs), with studies showing varied demographic focus and regional disparities in prevalence. Gender influences cleft condition ratios [8, 28]. Similarly, existing studies have shown some variations across gender and other social variables [29–31]. This rate varies between males and females, with 17.72 per 10,000 males and 15.78 per 10,000 females, respectively. This suggests a slight sexual dimorphism, with a higher prevalence in males [31]. The prevalence of live births with cleft lip and/or palate varies among different ethnic groups. For example, the prevalence is highest among those of mixed ethnic origins and lowest among those of Indian ethnic origin [31]. Another study found that OFC was more prevalent among Asian and Caucasian populations while African populations had the lowest [29].

Typically, in infants, factors such as anti-miscarriage medications, uterine wall abnormalities, and maternal stress may contribute to the risk of OFC. Female newborns were slightly more likely to develop cleft lip and cleft palate compared to male newborns [30, 31]. Additionally, research did not find that medication use during pregnancy increased the risk of OFCs in children. Consanguineous marriage was the most significant factor potentially increasing the risk of OFCs [30].

This study also found that clinical care retention is low, underscoring the need for targeted interventions and healthcare resources to address these disparities and improve outcomes [8, 28]. Another study also found low retention of clinical care for OFC [32]. The study explained that such low retention was due to the required multiple interventions, which often cause significant care burden [32]. Other causal issues include social and health-related anxieties, such as self-esteem concerns, fear of negative evaluation, and discrimination, which persist on a daily basis [32]. Despite the low retention found in this review, this review generally revealed some improvement in OFC care. For instance, Munabi and colleagues found that while 83.3% of general surgeons participated in short-term plastic surgery training, none performed cleft lip or cleft palate repair in their current practices [27].

It is important to address the burden of OFCs, not only as a medical condition but also due to their physiological challenges. Babai & Irving highlighted that OFCs pose a range of physiological challenges that affect feeding, speech, and overall development [33]. These challenges can result in increased stress, financial strain, and emotional burden on affected individuals and their families [34]. Hence, Kini recommended early diagnosis of genetic causes of clefts for early diagnosis and symptoms control. With the advancement in genetic testing and therapy, cleft detention/testing could be extended to fetuses for possible intrauterine interventions, such as surgical repair or gene therapy [35].

This review has highlighted the problems of specialist shortage and high OFC burden in Rwanda. This is not peculiar to Rwanda as the prevalence of OFCs is exacerbated by unique healthcare accessibility issues in Africa [1, 36–40]. The studies document critical shortage in oral health specialist across African countries [36–40]. For instance, many rural and remote areas lack specialized medical facilities, making it difficult for individuals to access necessary surgical interventions [12, 36, 37]. Sub-Saharan Africa often has few or no surgical centers capable of performing cleft repairs [1]. A shortage of trained healthcare professionals, such as surgeons, orthodontists,

and speech therapists, exacerbates the problem. A survey in East Africa revealed that many countries had fewer than one surgeon specialist per million people [7]. Where such services might be available, the accessibility problem is also compounded by economic challenges in the face of limited health insurance coverage.

The foregoing implies that performing surgical repairs of OFCs is fraught with difficulties in African contexts. Many hospitals in resource-constrained settings have limited surgical equipment and postoperative care facilities. Basic requirements, such as anesthesia and sterile surgical tools, are often in short supply [41]. Effective postoperative care, including speech therapy and orthodontic treatment, is rarely accessible. This can result in suboptimal outcomes, with patients experiencing persistent functional and aesthetic issues [42]. OFC care should be comprehensive involving surgeons, dentists, speech therapists, and psychologists. However, the fragmented healthcare systems in many African countries impede coordinated care [7].

Research gaps

There is a dearth of adequate recent studies on OFC in Rwanda since this review only found six eligible articles. More comprehensive epidemiological and sociomedical studies are needed to establish accurate prevalence rates, identify geographic or demographic disparities, and understand the sociocultural issues concerning OFC [1]. Rwanda has different provinces; it is important that studies cut across the provinces to assess the epidemiology and understand the risk factors. For example, there is a lack of research on the specific genetic, environmental, and nutritional factors contributing to OFCs in Rwanda. Identifying these risk factors is crucial for developing targeted prevention strategies.

There is currently insufficient research on the accessibility and geographical spread of healthcare services that can provide comprehensive care for OFCs. Research should assess the capability of the current healthcare infrastructure to manage cases of OFCs, which includes examining the presence of surgical facilities and well-trained professionals [7]. Gaining knowledge of the accessibility and efficacy of these services is crucial for enhancing overall patient results [43].

Limited information is available regarding the socioeconomic obstacles encountered by families seeking out-of-family care (OFC) in Rwanda. Research is necessary to evaluate the economic strain on impacted households and investigate possible methods of financial assistance or social protection in Rwanda. Gaining insight into the negative associations and misunderstandings might provide valuable knowledge for public health initiatives that aim to decrease societal obstacles to accessing healthcare. More qualitative research may be required to investigate the sociocultural factors that influence OFC management in Rwanda. Gaining insight into community perspectives and attitudes can provide valuable information for developing interventions that are culturally responsive.

Limitations and strengths

The review focuses on one country, Rwanda. While the findings are significant and could be generalized across Africa (especially, the sub-Saharan region), generalizing these findings to the entire African continent, particularly regions with advanced health systems like North African countries and South Africa, might not be entirely accurate. These regions have better healthcare infrastructure, which could lead to different challenges and solutions compared to Rwanda and other sub-Saharan countries. While the study specifically addresses OFCs, it underscores the necessity of broadening the focus to include the overall landscape of oral health.

The broader perspective is crucial as other oral health issues may pose unique challenges that require comprehensive attention to improve health outcomes. As previously observed, the reviewed studies did not include any social research that could signify challenges from the health demand side. Such studies could have also revealed whether there are misconceptions that could constitute a barrier to health access. The analysis emphasizes the importance of contextualizing findings within the broader African landscape and highlights the need for a comprehensive approach to oral health research. By addressing the identified gaps and recommendations, future research can contribute to more effective and equitable healthcare solutions for OFCs and other oral health issues in Rwanda and beyond.

Conclusion

This study reveals that Rwanda bears a considerable burden of orofacial clefts (OFCs), with prevalence varying significantly across demographics and ethnic groups. Notably, males exhibit a higher prevalence of OFCs compared to females, and differences in the occurrence of cleft lip and/or palate are evident among various ethnic groups. Key findings indicate that the clinical management of OFCs in Rwanda is hampered by low retention in care, a challenge compounded by the multiple interventions required and the associated social and health-related burdens. These findings underscore the pressing need for targeted interventions to address both the physiological and psychological challenges posed by OFCs.

Therefore, there is an urgent need to improve early detection of congenital anomalies, enhance prenatal care services, and expand access to specialized care facilities for infants with OFCs—especially those with additional malformations. Strengthening specialist support and ensuring continuity of care are also essential to improve

long-term outcomes for affected individuals. Overall, the findings serve as a call to action for healthcare policymakers and practitioners in Rwanda. Future research should focus on developing and evaluating innovative strategies to improve care retention and inform evidence-based health policies, ultimately aiming to reduce the burden of OFCs and improve the quality of life for those affected.

Abbreviations

AMED	The Allied and Complementary Medicine Database
CINAHL	Cumulative Index to Nursing and Allied Health Literature
MMAT	Mixed Methods Appraisal Tool
OFC	Orofacial cleft
PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews
USA	United States of America

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12903-025-05900-y.

Supplementary Material 1

Acknowledgements
Not applicable.

Author contributions
JM, PU, IEH, MCI, EN, JO, MAD, DDN, VA, GT, DZM, and KKK participated in study conception and design. JM, PU, IEH, MCI, EN, JO, MAD, DDN, VA, GT, and KKK refined and developed the primary search strategy. JA, JM, PU, LY, OO, and KKK were involved in drafting of the manuscript. JA, JM, AA, RDJ, and KKK were involved in reviewing of manuscript drafts. PU, IEH, MCI, EN, JO, MAD, DDN, VA, GT, and KKK performed data collection. JM and KKK performed data analysis. JA, JM, LY, and KKK provided critical revisions to the manuscript. PU and KKK provided supervision of all aspects of the protocol. PU, DZM, and KKK provided project administration. All authors read and approved the final manuscript.

Funding
This study was self-funded.

Data availability
The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate
Not applicable.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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Received: 5 April 2024 / Accepted: 27 March 2025
Published online: 18 April 2025

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