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Artículos

Down Syndrome People Caregivers' Knowledge and Perception of Oral Health: An Exploratory Review*

Conocimiento y percepción sobre salud oral de cuidadores de personas con Síndrome de Down: Una revisión exploratoria

Conhecimento e Percepção de Saúde Bucal de Cuidadores de Pessoas com Síndrome de Down: Uma Revisão Exploratória

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Abstract:

Background: Down syndrome (DS) is a genetic condition that can be associated buccomaxillofacially with periodontal disease, dentomaxillary anomalies, and eruption disorders. Caregivers should know how to prevent these oral pathologies. Purpose: To describe the knowledge and perception about oral health reported by caregivers of people with DS. **Methods:** This exploratory review followed the PRISMA-ScR guidelines, using PubMed, LiLACS, EMBASE, and EBSCO databases. It took place in September 2020, without limiting by date of publication or participants' age. It included publications in English and Spanish languages. **Findings:** 447 titles were found. After analyzing titles/abstracts and excluding duplicates, 16 studies were selected. After complete reading, 12 articles conformed the sample. **Discussion:** Although methods were heterogeneous among the studies, authors reported that the dentist has mainly instructed caregivers. Some have never received guidance on prevention of oral pathologies. Likewise, while family caregivers consider their children-with-DS oral health to be good, paid caregivers have a more negative perception. Challenges to finding dentists are common. **Conclusion:** The knowledge of most caregivers is satisfactory, and families perceive their children oral health to be good. However, studies that use valid and reliable instruments to verify these findings are lacking. A recommendation is to conduct clinical studies that allow to relate the degree of knowledge of caregivers with the oral health of children with DS.

Keywords: caregivers, dentistry, Down syndrome, knowledge, oral health, parents, perception, pediatric dentistry.

Resumen:

Antecedentes: El síndrome de Down (SD) es una condición genética que puede asociarse bucomaxilofacialmente con enfermedad periodontal, anomalías dentomaxilares y alteraciones de erupción. Es relevante que los cuidadores conozcan cómo prevenir estas patologías bucodentales. **Objetivo:** Describir el grado de conocimiento sobre salud oral reportado por cuidadores de personas con SD y su percepción respecto al estado bucodental de quienes tienen a cargo. **Métodos:** Esta revisión exploratoria siguió los lineamientos PRISMA-ScR, utilizando las bases de PubMed, LiLACS, EMBASE y EBSCO. Se realizó en septiembre de 2020, sin limitar fecha de publicación ni edad de los participantes. Incluyó idiomas inglés y español. **Resultados:** Se encontraron

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447 estudios. Después de analizar títulos, resúmenes y excluir duplicados, se seleccionaron 16 estudios. Luego de la lectura completa, se incluyeron 12 artículos. Discusión: Si bien los métodos fueron heterogéneos, los autores reportaron que los cuidadores han sido instruidos principalmente por el odontólogo; algunos nunca han recibido orientación sobre prevención de patologías bucodentales; asimismo, mientras los cuidadores familiares consideran buena la salud bucal de sus hijos con SD, los cuidadores remunerados tienen una percepción más negativa. Se reportan dificultades para encontrar un odontólogo tratante. **Conclusión:** El conocimiento de la mayoría de los cuidadores es satisfactorio y las familias perciben que la salud bucal de sus hijos con SD es buena. Sin embargo, faltan estudios que empleen instrumentos válidos y confiables que comprueben estos hallazgos. Se sugiere realizar estudios clínicos que permitan relacionar el grado de conocimiento de los cuidadores con la condición bucal de sus hijos(as). **Palabras clave:** conocimiento, cuidadores, odontología, odontología pediátrica, padres, percepción, salud oral, síndrome de Down.

Resumo:

Antecedentes: A síndrome de Down (SD) é uma condição genética que pode estar associada bucomaxilofacialmente com doença periodontal, anomalias dentomaxilares e distúrbios de erupção. Os cuidadores devem saber como prevenir estas patologias orais. **Objetivo:** Descrever o conhecimento e a percepção sobre saúde bucal relatados por cuidadores de pessoas com SD. **Métodos:** Esta revisão exploratória seguiu as diretrizes PRISMA-ScR, utilizando as bases de dados PubMed, LiLACS, EMBASE e EBSCO. Foi realizado em setembro de 2020, sem limitação por data de publicação ou idade dos participantes. Incluiu publicações nos idiomas inglês e espanhol. **Resultados:** Foram encontrados 447 títulos. Após análise de títulos/resumos e exclusão de duplicatas, foram selecionados 16 estudos. Após a leitura completa, 12 artigos foram incluídos na amostra. **Discussão:** Embora os métodos tenham sido heterogêneos entre os estudos, os autores relataram que os cuidadores foram orientados principalmente pelo dentista. Alguns nunca receberam orientações sobre prevenção de patologias bucais. Da mesma forma, enquanto os cuidadores familiares consideram boa a saúde bucal da criança com SD, os cuidadores remunerados têm uma percepção mais negativa. Os desafios para encontrar dentistas são relatados. **Conclusão:** O conhecimento da maioria dos cuidadores é satisfatório, e as famílias percebem a saúde bucal de seus filhos como boa. No entanto, faltam estudos que utilizem instrumentos válidos e confiáveis para verificar esses achados. Recomenda-se a realização de estudos clínicos que permitam relacionar o grau de conhecimento dos cuidadores com a saúde bucal de crianças com SD.

Palavras-chave: conhecimento, cuidadores, dentista pediátrico, odontologia, pais, percepção, saúde bucal, Síndrome de Down.

INTRODUCCIÓN

Health care delivery must be a comprehensive and continuous process that focuses on the person, the family, and the community. Thus, health teams should prioritize health promotion and disease prevention activities, along with delivering self-care tools to people and communities. The latter are active participants in this process. Therefore, dental care must integrate a family and community approach that considers the preferences and beliefs of all stakeholders (1). This argument is based on the biopsychosocial model that recognizes and incorporates social determinants as factors that influence the health-and-disease process (2). The social determinants of health are the conditions in which people are born, grow, live, work, and age. They include factors such as socioeconomic status, education, neighborhood and physical environment, employment, and social support networks, as well as access to health care (3,4).

From a biopsychosocial perspective, together families and caregivers hold a foremost role as a social determinant because, among their tasks, they must provide preventive and promotion care in oral health, especially when they take care of people with disabilities, such as those with Down Syndrome (DS) (5,6). Therefore, the knowledge of caregivers could impact both the execution of dental treatments and the success of oral health interventions and maintenance of those they look after (7).

DS is one of the most common genetic conditions worldwide. Its cause is a trisomy in the 21st pair (8,9). In recent years, DS rates have been increasing in Latin America. Chile has an incidence higher than 2.2 per 1,000 births, one of the highest in the region (10). People with DS can present different morbidities such as intellectual disability, congenital heart defects, and gastrointestinal abnormalities. In the oral cavity, skeletal and respiratory anomalies, periodontal disease, and eruption alterations are frequent (11).

Due to the high probability of developing oral pathologies, prevention and promotion at an early age can be key to avoiding irreparable long-term damage (5,6). Therefore, recognizing caregivers' knowledge and perception on this condition could be of significant help for the treating dentist to implement educational plans that are consistent with the needs of each patient and their family. Since there is not a current review that brings together available evidence on this topic, the aim of this exploratory review was to determine the amount of knowledge about oral health reported by caregivers of people with DS and to describe their perception regarding the oral health status of those they look after.

MATERIALS AND METHODS

The following exploratory review followed the methodological structure and recommendations published by Arksey and O'Malley (12) and in accordance with the guidelines outlined in *Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols for Scoping Reviews* (PRISMA-ScR) (13). The research question observed the PCC format (*population, concept, context*) (14). It considered "fathers, mothers and/or caregivers of people with Down Syndrome" (P); "knowledge and perceptions in oral health" (C); and "validated instruments, interviews, questionnaires" (C).

Search Strategy and Databases

An electronic search took place in September 2020 in the following databases: Embase, PubMed, LiLACS, and EBSCO. The search strategy was adapted to each database with the following key terms and Boolean operators, alone or in combination, where applicable: (*conocimientos* OR *knowledge* OR *perceptions* OR *attitudes* OR *opinion* OR *education* OR *understanding* OR *awareness*) AND (*caregivers* OR *parents* OR *families* OR cuidadores OR padres) AND (*oral health* OR *salud oral* OR *mouth care* OR *oral hygiene* OR *oral care*) AND (*down syndrome* OR *sindrome de down* OR *trisomy 21*).

Eligibility Criteria

Inclusion criteria were primary studies published in English or Spanish that measured the knowledge or perception of oral health of caregivers of people with DS through questionnaires or interviews. There were no limits regarding participants' age or publication date. Exclusion criteria were publications with no full text available, populations that did not include DS, interventions without an instrument to measure desired outcomes/results, or that did not assess knowledge/perception.

Data Recording and Synthesis of Findings

Three members of the research group independently selected the articles, following the inclusion and exclusion criteria. The team compared and discussed the studies, emphasizing research purpose, methodology, population, and main results obtained. Article registration met Arksey and O'Malley's (12) criteria, to include: authors, title, place of study, purpose, participants, methodology, outcomes measures and main findings.

RESULTS

Study Selection

Figure 1 presents the study selection process using a PRISMA flowchart (13). The electronic search returned 447 results of which we eliminated 12 duplicates, leaving 435 titles for screening. The screening process eliminated 419 articles after reading titles and abstracts for not being relevant to answer the PCC question or because they were not primary studies, giving a total of 16 eligible studies for full-text reading. Then 7 did not have full-text available, did not include any instrument (i.e., interview or questionnaire) to measure desired outcomes, or was not conducted with the specific population with DS looked at in this review. After completing the full-text readings and having identified studies from other sources (i.e., references from articles selected) which added 7 titles. Three of the latter articles were excluded due to duplications and one did not have full text available. The final sample consisted of 12 articles.

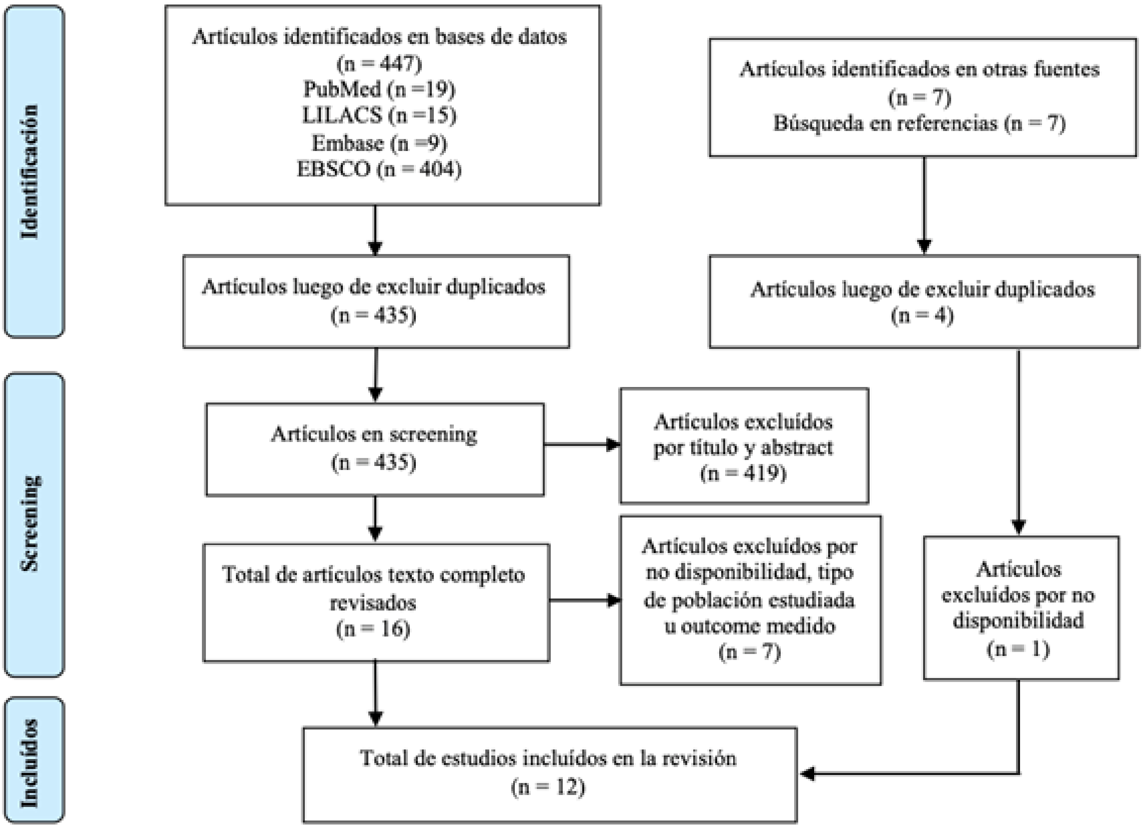


FIGURE 1

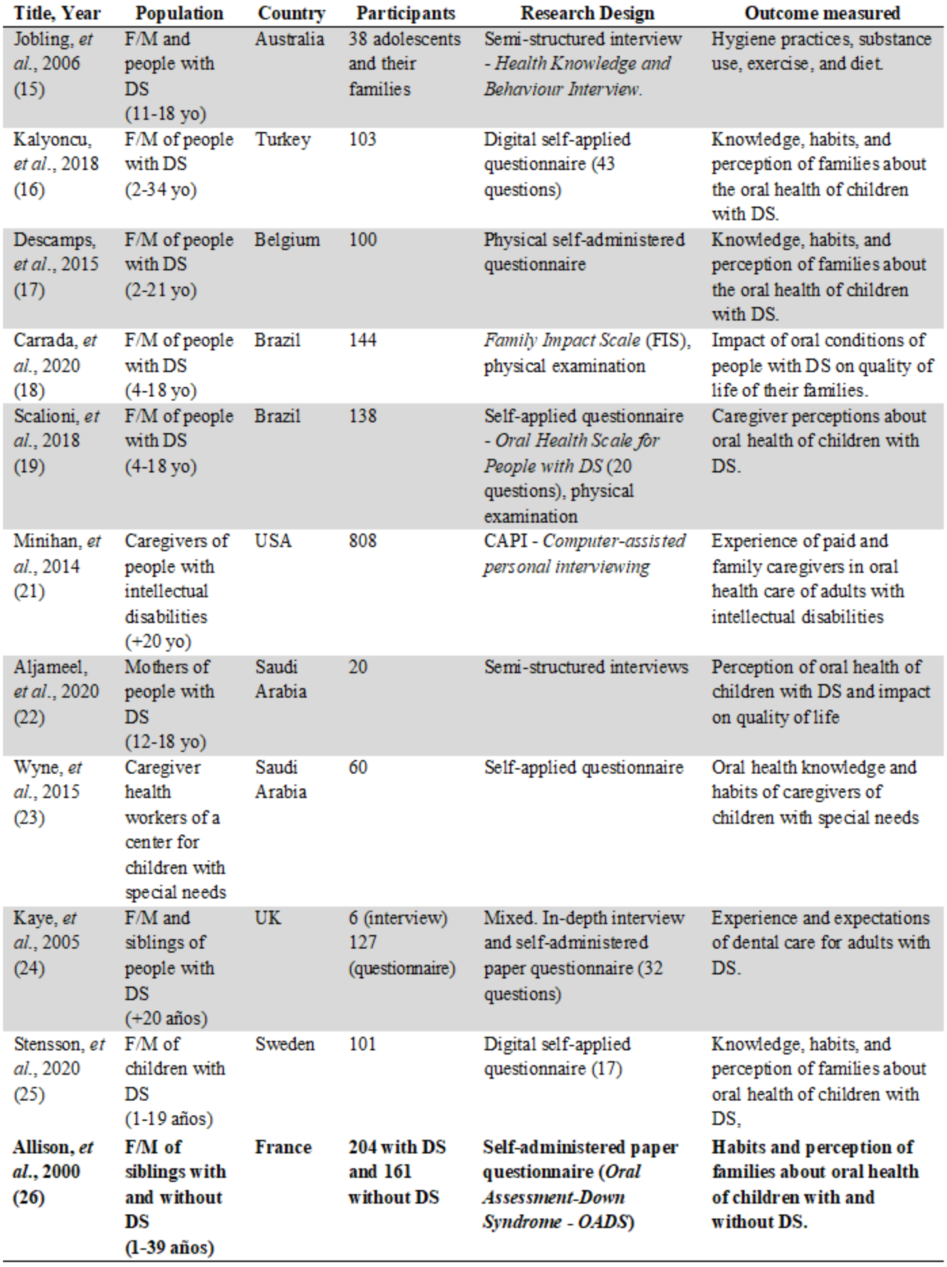
PRISMA Flowchart of the Exploratory Review (13)

Source: the authors.

Description of Studies Included in the Review

The 12 studies included in the review are in Table 1. The places of the studies included 9 countries: Australia (15), Turkey (16), Belgium (17), Brazil (18,19,20), United States (21), Saudi Arabia (22,23), United Kingdom (24), Sweden (25), and France (26). Most studies were from Europe and one in Brazil.

TABLE 1
Characterization of the Studies in the Review



Title, Year	Population	Country	Participants	Research Design	Outcome measured
Jobling, *et al.*, 2006 (15)	F/M and people with DS (11-18 yo)	Australia	38 adolescents and their families	Semi-structured interview - *Health Knowledge and Behaviour Interview.*	Hygiene practices, substance use, exercise, and diet.
Kalyoncu, *et al.*, 2018 (16)	F/M of people with DS (2-34 yo)	Turkey	103	Digital self-applied questionnaire (43 questions)	Knowledge, habits, and perception of families about the oral health of children with DS.
Descamps, *et al.*, 2015 (17)	F/M of people with DS (2-21 yo)	Belgium	100	Physical self-administered questionnaire	Knowledge, habits, and perception of families about the oral health of children with DS.
Carrada, *et al.*, 2020 (18)	F/M of people with DS (4-18 yo)	Brazil	144	*Family Impact Scale* (FIS), physical examination	Impact of oral conditions of people with DS on quality of life of their families.
Scalioni, *et al.*, 2018 (19)	F/M of people with DS (4-18 yo)	Brazil	138	Self-applied questionnaire - *Oral Health Scale for People with DS* (20 questions), physical examination	Caregiver perceptions about oral health of children with DS.
Minihan, *et al.*, 2014 (21)	Caregivers of people with intellectual disabilities (+20 yo)	USA	808	CAPI - *Computer-assisted personal interviewing*	Experience of paid and family caregivers in oral health care of adults with intellectual disabilities
Aljameel, *et al.*, 2020 (22)	Mothers of people with DS (12-18 yo)	Saudi Arabia	20	Semi-structured interviews	Perception of oral health of children with DS and impact on quality of life
Wyne, *et al.*, 2015 (23)	Caregiver health workers of a center for children with special needs	Saudi Arabia	60	Self-applied questionnaire	Oral health knowledge and habits of caregivers of children with special needs
Kaye, *et al.*, 2005 (24)	F/M and siblings of people with DS (+20 años)	UK	6 (interview) 127 (questionnaire)	Mixed. In-depth interview and self-administered paper questionnaire (32 questions)	Experience and expectations of dental care for adults with DS.
Stensson, *et al.*, 2020 (25)	F/M of children with DS (1-19 años)	Sweden	101	Digital self-applied questionnaire (17)	Knowledge, habits, and perception of families about oral health of children with DS,
Allison, *et al.*, 2000 (26)	**F/M of siblings with and without DS (1-39 años)**	**France**	**204 with DS and 161 without DS**	**Self-administered paper questionnaire (*Oral Assessment-Down Syndrome - OADS*)**	**Habits and perception of families about oral health of children with and without DS.**

(F/M: fathers and mothers. DS: Down Syndrome. yo: years old)
Source: the authors

Regarding research designs, methodologies were quantitative (16,17,18,19,21,23,25,26) and qualitative (15,20,22), and one study used mixed methods (24). Questionnaires were the most used data-collection instrument, some developed by other authors also included in this review. For example, several studies used the *Oral Assessment in Down Syndrome* (OADS) instrument created by Allison and Hennequin (27). On the other side, Stensson (25) translated, validated, and applied the questionnaire created by Descamps *et al.* (17). Application means were print or online; assisted or self-applied.

Studies in this review included the 2000–2020-year interval. The main purpose was to determine the knowledge, habits, and perception of families about the oral health of children with DS and how it impacted their quality of life. The main populations of study were fathers and mothers of people with DS. Other studies looked at the experience of mothers, formal caregivers, and health care professionals who performed care tasks for these people.

DISCUSSION

In this exploratory review, 12 primary articles studied oral health knowledge of caregivers of people with DS or described their perception regarding the oral health of those they care for. A limited number of studies addressing this issue was available. In addition, the studies showed methodological heterogeneity as some used non-validated questionnaires or no psychometric analysis. Worldwide, more rigorous studies of such issues were from Europe, while in Latin America, only one methodologically appropriate study from Brazil related to the purpose of this review.

Caregiver Perception of Oral Health

Parents who reported their children had good general health also considered their oral health to be adequate (17,25). In general, most families rated the oral health of their children with DS as good or very good (16,17,19,20,22,25). However, a study (21) showed that formal or paid caregivers outside the family, with a statistically significant difference, have a more negative perception of oral health than family members who play the caregiver role. This could suggest the existence of an emotional-family component in the perception of oral health of relatives with DS. On the other hand, a negative perception was more likely when there were malocclusions or the child was between 4 and 9 years of age, the latter due to a greater need for adult supervision since, in most cases, people with DS cannot brush their teeth autonomously (19). Parents who perceive poor oral health in their children also stated that the clinical examination and dental treatment were difficult procedures to perform (25).

Regarding the greatest concerns of caregivers about oral health issues, these focused on caries, pain, and periodontal disease (19,21,22,24). Oliveira, *et al.* (20) recognized an important cultural component in which mothers believe that the main cause of caries in their children is the constant consumption of antibiotics due to recurrent infections, which can be common at an early age of a child with DS (5,9).

The caregivers identified in their children the presence of halitosis, inflammation, and bleeding gums (21,22). Likewise, mothers noted that pain affected their children's mood or general behavior, perceiving crying and anger as indicative signs of the presence of dental pain in children (22).

Knowing how to maintain proper oral hygiene is also another major concern for caregivers. This is due to the need to reinforce or brush teeth, given the lack of manual dexterity or intellectual disability that people with DS may have (19,24). In addition, they reported that home oral care routines are interfered with by behavioral problems, lack of time, or lack of sufficient help to carry it out (21).

Caregiver Perception of Dental Care

Caregivers were concerned about oral hygiene and taking their children for frequent dental check-ups, attending at least once a year (16,17,24). The fathers and mothers who participated in those studies reported the need for an annual check-up, presence of caries, pain, being referred by a health professional, or accompanying siblings as the main reasons for visiting the dentist (16,17).

However, this study also found that 24.2% of families had never taken their children to the dentist (16). When examining the justifications for not doing so, it was found that most families thought their children were too young to go, which was consistent with another study by Descamps, *et al.* (17), in which it was pointed out that children between 2 and 4 years old had never been to the dentist, because their parents considered them too young. Caregivers also reported as reasons for being apprehensive about dental care: assuming that children would be difficult to care for, being unaware of the need to visit the dentist preventively and considering that general health problems were more important than oral health issues (16).

Access to dental care was another issue mentioned by caregivers who reported that they found challenging to find a competent dentist (16,18,26). This affects the frequency of annual visits since they are fewer for not finding a trained professional (26). When comparing the experience of children with DS with that of siblings without this condition, those who did not have this syndrome had a significantly higher probability of having received dental care than the sibling with DS (26). Also, the main dental procedures performed on children with DS were extractions and restorations and that, except for hygiene instruction, very few received preventive care, such as the application of sealants or fluoride varnish (24). In 35% of the families, the child with DS saw the same dentist as her siblings (25) and 57.5% saw the same dentist as their relatives (24). Caregivers also expressed that it would be useful for them to have a list of dentists trained to provide dental care to their children with DS (24).

Finally, caregivers indicated having different dental care experiences; however, the majority (84%) was satisfied with the professional caring for their child (25). In their opinion, it is more important for dentists to be friendly, reassuring, and able to explain procedures before treatment, involving the patient, than someone specialized in treating people with special needs (16,17,24).

Impact on Quality of Life

Although there are no differences regarding how oral health status impacts the quality of life of families of children with or without DS, the parents of the former perceived that situations such as presenting dental caries and leaving them untreated, do have a negative impact on the quality of life of those around them (18). For example, a poor oral condition can directly affect the mood of mothers who reported feeling guilty and neglectful if their children had dental pain (22). Likewise, poor oral condition, halitosis, or aesthetic compromises (20) could alter the child's quality of life and, consequently, the quality of life of the people who care for them. Mothers saw themselves as the most affected member within the family circle, especially when there is pain involved, indicating that they felt irritated, angry, and depressed, preferring to isolate themselves socially until the child felt better (22). Regarding the latter, problems affecting oral health would constitute an obstacle to the child's social acceptance, since pain or dentomaxillary anomalies associated with alterations in orofacial functions, such as speech, breathing and chewing, can disturb their emotional status, leading to a restriction in family activities and generating conflicts within the family (20,22).

Caregiver Knowledge of Oral Health of People with DS

Most caregivers recognized the importance of oral health in chewing, aesthetics, and speech. In addition to being aware that having good oral hygiene is necessary for good general health, they reported having adequate knowledge of dental preventive care and self-care and recognized the influence of a high-sugar diet as the main cause of caries development (23). Likewise, they affirmed the importance of frequent visits to the dentist and brushing teeth, emphasizing this oral hygiene habit as a rule within the home (15,17,23). Regarding the use of fluorides, most caregivers had heard of its role in preventing cavities and only 25% attributed the property of favoring teeth whitening to it. The majority (93.3%) recognized toothpaste as the main source of fluoride and to a lesser extent (20%) drinking water (23).

For the most part, families received information on these topics from a dentist (16,17,21,23,24,25). Other recognized sources of information were teachers, professionals working in rehabilitation centers, and the

Internet (16,17,23). Talking with other parents of children with DS was also considered an important way of learning (24,25); even in one study (24) this practice was pointed out as more useful than asking a health professional directly. It was further noted that, unlike unpaid caregivers, formal or paid caregivers commonly receive training and formal apprenticeship through courses (21). Despite this, a study reported that 20 % of parents had never received any type of guidance regarding the oral status of child with DS (17).

Regarding the knowledge acquired, caregivers declared that they have received education on prevention and promotion measures; for example, oral hygiene instruction, dietary counseling, and use of fluorides, as well as information on common oral conditions in DS, including tooth agenesis and delayed tooth eruption (17,25). 47.5 % rated such teaching as appropriate, and the majority stated that it would be useful to have a brochure with advice on oral health problems commonly associated with DS (24).

CONCLUSIONS AND RECOMMENDATIONS

The knowledge of topics related to oral health reported by most caregivers is satisfactory; they recognize the appropriate measures to prevent oral pathologies.

Although families indicate that the oral health of their children with DS is good, they also recognize that access to dental care should be easier, being essential for them that the professional be friendly, respectful, and focused on the patient needs. Dental health professionals should also provide caregivers with the necessary tools to prevent oral health status from negatively impacting the quality of life of people with DS and those around them.

The methodological heterogeneity of the included studies is a limitation for this review, making it impossible to determine exactly whether the knowledge of parents and caregivers of people with DS impacts their oral status. There is a lack of studies that use valid and reliable instruments to verify these data.

A recommendation is to conduct clinical studies that to associate the knowledge of caregivers with the oral condition of their children with DS.

Acknowledgments

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Notes

* Original research.

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