

# Families' experiences in oral health care of Down Syndrome children from a foundation in Bucaramanga, Colombia

## Experiencias de familias en el cuidado de la salud bucal de niños con Síndrome de Down de una Fundación en Bucaramanga, Colombia

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### Abstract

**Introduction:** several studies highlight the importance of the relationship between family dynamics and oral hygiene in people with intellectual disabilities. In the case of children with Down Syndrome (DS), the studies generally focus on clinical aspects, disregarding the factors that can influence the way families experience oral health care. Understanding these experiences is key to contributing from the professional practice to the improvement in the quality of life of this population group. **Methods:** qualitative, phenomenological study in eight families of children with DS, using in-depth and episodic interviews. **Results:** the experiences go beyond good hygiene practices, since caregivers tend not to separate other fundamental aspects of their children's lives. This is important from a comprehensive view of human beings, their health and care. The experiences are characterized by a preeminence of females' roles and the fathers' absence or presence, in addition to daily experience, social support, and opportunities. **Conclusions:** experiences during oral hygiene practices in families are gratifying in cases where they discover that their children become autonomous to carry out their own oral health care. In most families, mothers accompany and reinforce. However, it was shown that women feel they are not capable enough to help their children when they notice no progress in children's autonomy to perform their own oral health care.

### Keywords:

families, life-changing events, childcare, Down Syndrome, oral health

### Resumen

**Introducción:** diversos estudios han destacado la importancia de la relación entre la dinámica familiar y la higiene bucal de personas con discapacidad intelectual. En el caso de niños y niñas con Síndrome de Down (SD), los estudios se orientan con mayor frecuencia a la revisión de aspectos clínicos; los factores que pueden influir en la forma en que las familias viven y experimentan el cuidado de la salud bucal han sido menos explorados. Comprender estas experiencias resulta entonces de vital importancia para aportar desde la práctica profesional a la mejora en la calidad de vida de este grupo de población. **Metodología:** estudio cualitativo con enfoque fenomenológico, con ocho familias de niños con SD. Se utilizaron entrevistas en profundidad y episódicas. **Resultados:** las experiencias van más allá de buenas prácticas de higiene, pues los cuidadores no desligan otros aspectos fundamentales de la vida de sus hijos. Esto resulta importante desde una visión integral del ser humano, su salud y su cuidado. Se caracterizaron por la preeminencia del rol femenino, su influenciadas por la ausencia o presencia paterna, y se nutren además de la vivencia cotidiana, el apoyo social y las oportunidades. **Conclusiones:** las experiencias durante las prácticas de higiene bucal en el entorno familiar son gratificantes en los casos en que descubren que sus niños tienen autonomía para realizar sus propios cuidados. En la mayoría de las familias, las madres acompañan y refuerzan. Sin embargo, se evidenció que las mujeres se perciben con poca capacidad para ayudar a sus hijos cuando observan que no hay avances en la autonomía para asumir su propio cuidado.

### Palabras clave:

familias, acontecimientos que cambian la vida, cuidado del niño, Síndrome de Down, salud bucal

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## INTRODUCTION

The oral health condition of children with Down Syndrome (DS) relies heavily on the family's commitment and responsibility in supporting them in oral hygiene practices, considering their difficulties in developing autonomy and motor skills.<sup>1</sup>

A study in Argentina showed that children and adolescents with DS attending specialized educational institutions had many oral cavity alterations associated with underlying factors according to their phenotype; it also found that psycho-socio-cultural factors were highly influential in the development of oral pathologies, and that these patients have difficulties in accessing dental treatment.<sup>2</sup>

Kaye's study showed that the oral health care experience was influenced by dentists' attitudes and skills, stigma, family beliefs, information, and support, highlighting the importance of timely guidance on oral health in children's earlier years; finding sympathetic dentists with knowledge on DS is also critical.<sup>3</sup>

Oral health care experiences can be very stressful due to the negative attitudes of DS children, which are not connected to the disability but to the result of parenting errors, most of which result from lack of counseling.<sup>1,4</sup>

A study in the West Indies found that parents showed positive attitudes towards oral health, but the barriers and challenges to achieving the ideal preventive care for their children, in relation to healthy diet, oral hygiene and dental care, coupled with all the other responsibilities at home, affected their attitudes to the point that their experiences became negative. They felt they needed

practical guidance on oral health care and more access to dental treatments.<sup>5</sup>

Upon the arrival of a child with DS, women are generally more responsive than men, as they become the main caregivers and focus all their attention on their child's care, and this produces a greater physical and emotional burden, as they are more concerned with their child's future.<sup>6</sup>

In a literature search, no studies were found on families' and caregivers' experiences in oral health care of DS children in Santander, Colombia. The aim of this study was to describe families' experiences in the oral health care of DS children who attend a foundation in the city of Bucaramanga, Colombia.

## METHODS

A qualitative study with a phenomenological approach was carried out in 12 family members of 8 children who regularly attended a foundation in Bucaramanga during 2017 and 2018.

Phenomenology was adjusted to what was being explored in this research project in order to approach the subjects' experiences in relation to various situations of their daily lives.<sup>7</sup> Husserl's proposed descriptive methodology was used to describe the meanings of everyday experiences as perceived by their protagonists.<sup>7,8</sup>

Logical sampling was used, which consisted of working with the family members who had one characteristic in common: being responsible for the oral health care of DS children attending a foundation in Bucaramanga.

The Ethics Committee of Universidad Santo Tomás at Bucaramanga approved the project on June 3, 2017.

A meeting with parents was held at the foundation to present the study's objectives and some agreed to participate voluntarily. They signed an informed consent and then each participant was contacted to agree on the day and place to conduct the first interview.

At the first meetings, semi-structured 2-hour interviews were conducted for an initial contact, seeking empathy with the interviewees so that they felt confident in sharing their experiences. Some guidelines were developed for the researchers so that they kept focused on the study's objectives. The interviews were recorded with the participants' consent.

The second phase included episodic interviews with mothers. In these interviews, the researchers favored a more open dialogue with the participants. The following items were considered:

- Specific episodes narrated spontaneously
- Repeated episodes of oral health care situations
- Examples evoking specific situations during dental care.

As interviews were completed, they were transcribed to determine the need to confirm or deepen some relevant information.

In this article, the protocol descriptions corresponding to one of the first two stages of the study are reported following Husserl's

phenomenology.<sup>9</sup> The two stages are described below:

- Application of epoch : the interviews were transcribed, taking into account the field notes. The material was read searching for structures and meanings.
- Description of participants' experiences: this corresponds to protocol descriptions, which consist of stories by the researchers of each participant's experiences as expressed in the interviews. To protect the participants' personal data, identifiers were used.

Once the protocol descriptions were made, two researchers were invited to compare them with the transcribed interviews and find correspondences.

They were later shared with the families to confirm that the descriptions corresponded to what the participants expressed.

## RESULTS

The results correspond to the first stage of the investigation. Therefore, the protocol descriptions are presented instead of final results. The participants' ages ranged from 19 to 73 years. Two fathers, 8 mothers and 2 sisters were interviewed. As for the families, 4 women had a stable relationship with their partners, 3 were abandoned after their children were born, and one emigrated from the rural area to the city in search of better rehabilitation opportunities for her child. Table 1 shows the participants' description.

**Table 1.** Description of participants

No.	Participant	Age	Occupation	Relationship between parents	Child's sex	Child's age	Family Type
1	Mother	49	Homemaker	Poor	Male	12	Single parent
2	Mother	44	Homemaker	Bad	Male	10	Reconstituted
3	Sister	19	Student	Bad	Male	10	Reconstituted
4	Mother	39	Seamstress	Poor	Male	6	Single parent
5	Mother	46	Accountant	Good	Male	10	Nuclear
6	Mother	53	Seamstress	Bad	Male	11	Single parent
7	Father	50	Retired	Good	Male	11	Nuclear
8	Mother	54	Homemaker	Good	Male	11	Nuclear
9	Mother	45	Cobbler	Bad	Male	10	Single parent
10	Mother	59	Homemaker	Good	Female	15	Nuclear
11	Sister	23	Student	Good	Female	15	Nuclear
12	Father	73	Cobbler	Good	Female	15	Nuclear

Source: by the authors

All families knew their children had DS at birth. Some doctors were assertive in communicating the news to them. Some fathers felt encouraged to take on the new challenge, while others did not provide information to guide the start of a new upbringing. In some families, the fathers abandoned their women. Therefore, in some women this news caused depression, grief, and loneliness "The process of realizing that my child had Down Syndrome was sorrowful, as when someone close to you dies, until you accept it". They had to go alone through the anxieties of some surgeries that their children needed due to systemic conditions. "He had to undergo bone marrow transplant".

The support networks included their mothers, sisters, other children, friends, and some specialized institutions. "Apart from nanny and I, my mommy is very much

concerned, and also my sisters". However, they have felt discrimination and rejection towards their children by educational institutions, as they have faced difficulties to find a place. "I have had many difficulties to get him in", as well as physical and emotional abuse from other students, "you feel bad that your son is rejected and treated the way my child was treated". They also experienced negligence concerning dental care by some practitioners. "No one has told me anything about his crooked teeth".

Below is a description of the oral health experiences of caregivers of DS children.

### AC1 experience

49-year-old mother. Accountant. She had to quit her job to devote herself to caring for her son.

She stated that she was not worried about his teeth not erupting, as she was more concerned with other examinations of his heart, limbs, and sense organs. She neglected oral health as she says she was not aware of the importance of teeth and their care.

An experience she remembers with sorrow had to do with the attitude by the child's father towards a dental procedure that was performed under general anesthesia. He didn't agree with the procedure as he was afraid something would happen to the child, so he threatened with killing her if something happened to his son. "My husband threatened me that if something happened to the child, he would have me dead".

She thinks that dental professionals should provide more guidance by educating families and children about brushing practices.

She recognizes that the foundation has been key in developing her child's autonomy, because he has improved his behavior. Finally, she says that God has given her strength to understand and be able to help his son: "I ask God for so much help".

### **AC2 and AC3 experience**

44-year-old mother, homemaker, and her daughter, 19-year-old college student.

It wasn't easy for her to accept the new arrival, "I felt like I wanted to die". She needed psychiatric help and was medicated for a long time. "I mean, I didn't take it that my kid came with Down Syndrome".

The father did not accept the child's condition and decided to leave. Her older daughter helps with the child's care, reinforcing hygiene habits, which helps improve care experiences.

Her experience in caring for her child's oral health at home has been difficult, frustrating, and even intimidating, yet she has been able to manage. The child does not brush his teeth on his own and does not accept the use of dental floss; they don't use mouthwashes because he suffers from reflux and was prevented from using it. "Whenever I go to the bathroom, I try to wash my mouth in front of him so that he sees that it's necessary, because he doesn't want to get it".

As for dental care, their experiences have been full of distress and concern because the procedures have been done under general anesthesia.

### **AC4 experience**

39-year-old mother. She works as a seamstress.

Her hardest experience was seeing his teeth stained. "The doctor told me nothing. And since you don't know, you do as the doctor says". Her child brushes on his own but doesn't apply enough force, and he does not use dental floss.

She has only taken her child to the dental office once and her experience was satisfactory, as she feels the child was treated well. "The doctor spoke to him and explained that what she was going to do to him would not be painful; he did very well, and the doctor extracted it quickly".

### **AC5 experience**

43-year-old mother. Accountant.

She is committed to her child's care; she wants to support him to avoid any major problems with his teething, as he needs it, and deserves to be and feel good. She remembers sadly that when he was younger, she was told that nothing could be done to

treat his teeth, and that's why the kid has so many cavities.

A rewarding experience in caring for her child's oral health was the first time she saw him brushing his teeth alone; he was two years old and for her it was a wonderful moment. She claims this is thanks to the guidance and therapies received at the foundation, which significantly improved his oral health. She clarifies that, even though the child brushes his teeth by himself, the nanny, she, or the father are always nearby supervising and reinforcing him; they floss him to get the best oral hygiene.

Her experience bringing the child to the dental office has been very rewarding: "A wonderful experience in oral health care is that he is not afraid of the dentist". However, there was an unpleasant experience once when the dentist was not patient enough and tied him to the chair with a sheet. As a result of this experience, it was hard for him to re-enter treatment.

Another experience caused indignation and disappointment on her due to a dentist's behavior as she felt the kid was being discriminated. "I will never forget the doctor's concept as he said that it does not matter if his teeth are twisted or damaged. I think it's terrible that they do not consider them as persons with full rights".

### **AC6 experience**

53-year-old mother. She works as a seamstress.

She had to go through a grieving process to accept the child's condition. The father lives nearby, but has not kept any contact with his son.

The child is autonomous for his brushing and seeks her reinforcement. However, she

stated that "it is hard with them because I tell him to brush all the teeth, but he doesn't, he focuses on just one, the one here at the front". He doesn't use mouthwash because she has not been able to buy it. When she has to go to work, her sister takes care of the child, but she does not supervise his brushing.

She feels well when she takes her child to the dentist because he likes it and shows a good attitude. But she feels that the service could be better, "There, they insisted on the Band-Aid and I did not feed him at once and yet they would fall". Also, they have never mentioned any treatment to correct "the child's crooked teeth". These experiences make her feel insecure, as she does not find support from dental practitioners.

### **AC7 and AC8 experience**

54-year-old mother, homemaker, and 50-year-old father, retired.

The mother had to quit her job to devote herself to caring for her son. At first, the experience in oral health care was difficult because the child did not allow her to help him brush; he would not open his mouth and would reject her, making her feel concerned and helpless, as she did not know how to help him.

She claims that the directions given by a therapist helped the child improve oral cleaning practices. "I am glad that I was able to do it".

She didn't like one dentist's attitude, "I asked the doctor what he was doing because they looked crowded. He asked me to feed him tostones [fried plantain] and nougat, and they would fall off", which was a very daunting experience. She states that the support offered by dental practitioners is a key factor as it can

help caregivers provide the adequate care for a good oral health. She thinks that specialized institutions could help them, but they can't afford a private service.

### **AC9 experience**

45-year-old mother. She works as a cobbler.

She had a sad experience after giving birth, as the father abandoned them once he knew about the child's condition. "I cried for two years, because I didn't accept that he was born that way". The child brushes himself and in his own way. She has only taken him to the dentist once, and she felt that her child was taken care of very well because the dentist was affectionate and did not show any signs of discrimination.

The child has had serious health complications that overall have been taken care of, and she acknowledges that for this reason she has neglected oral health care. "Because of that, as I am telling you, I had to quit my job in factories". She feels good about herself for dedicating all the time to her son, because while she was working in factories the child was abused by the women taking care of him: "When it was time to start giving him soups and the child could not eat, she would beat him".

### **AC10 - AC11 and AC12 experience**

A 73-year-old father who works as a cobbler. A 59-year-old mother who is a homemaker and does catalog sales, and a 23-year-old daughter with no occupation.

The mother is very dedicated and constant with the therapies and rehabilitation offered at the foundation, which translates into the full development of her daughter's autonomy, who attends a regular school. "She gets up by herself in the morning to go to school, comes back at noon, and gets

dressed and waits for the shuttle to go to Fundown. It's been 13 years that she goes to Fundown. She's excited about the shuttle, it's the first time she uses it to go there".

The girl brushes herself; however, the mother sometimes reinforces her. She has not used dental floss. Her experience during dental visits is satisfactory as she sees the girl's good attitude and interaction with the dentists, who have treated her well. The father and older sister are not involved in the supervision and support of hygiene practices. The father believes that rehabilitation through the foundation has been good and recognizes his wife's dedication to achieve his daughter's progress. The sister states that she has not been involved in her care and that coexistence has been easy, because she feels her sister is a normal child.

The mother thinks that the foundation's support has been positive because they teach her daughter hygiene habits.

## **DISCUSSION**

The results of this study show that the experiences in oral health care of DS children are assumed by mothers in most families, which represents an extra burden in their role as mothers, as they experience distress and loneliness due to the absence of the fathers' participation and commitment. The studies by Huiracocha, Su rez and Descamps confirm the idea that the care role is mostly allocated to women.<sup>4,6,10</sup>

This experience is mediated by various aspects, including the relationship with the family, the surroundings and with the due pertinent official institutions. However, each caregiver manages and lives the experience

in his or her own way, going through different stages, from birth to knowing the news, to adapting to the new challenges and forms of coexistence.<sup>11,12</sup> The impact of knowing the news of having a child with DS produces many different feelings in parents, including distress, uncertainty, anguish, and even manifestations of neglect and denial of a reality that must be assumed from birth, leading to abandoned mothers, whose lives are transformed as they are the only responsible for their child's care.<sup>6,12,13</sup>

Female caregivers are empowered persons, determined to do whatever is necessary for the well-being of their children, but also with several limitations that they voluntarily accept, but which in turn prevent them from acting effectively. Some have quit their jobs to work at home, while others work extended hours to meet financial needs, and in some cases they even lose their identity, as Saavedra points out.<sup>14</sup>

However, the hope placed on their children as people they can bring to society gives them renewed strength and help them continue to support them. This agrees with the expressions by the women in the studies by Huiracocha and Suarez.<sup>4,6</sup>

The influence of fathers' role in care experiences has also been identified. In some cases they just abandon the families, denying the economic and emotional commitment, and leaving all the responsibility to the women, who feel lonely and yearn for support in order to devote as much time as possible to accompany their DS children. However, in those families where the father did not leave, an active involvement of fathers in care is not seen. This is not the case with the parents of Marriaga's study, where a positive parental response is decisive for a shared care experience.<sup>11</sup>

The role of fathers is influenced by gender-based social constructs, where care is attributed to women, while men take other roles or have difficulty coping with the reality of DS. The need to advance towards a positive transformation of the male role in care becomes evident, as the experience of women caregivers is adversely affected by the absence of parental responsibility, as documented in studies showing that positive parental bonding improves care experiences.<sup>15</sup>

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## CONFLICTS OF INTEREST

The authors state that they have no conflict of interest.

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