Mothers’ perceptions concerning oral health of children and adolescents with Down syndrome: a qualitative approach

Aim The aim of this qualitative study was to investigate the perceptions of a group of mothers of children and adolescents with Down syndrome (DS) concerning the overall health and oral health of their children. Methods The information was collected interviewing in depth 19 mothers using an open-ended orientation form. To investigate the perceptions of the mothers was carried out a thematic content analysis. Two general themes were addressed: mothers’ perceptions concerning the health of the child with DS and mothers’ opinion on the impact of oral health on the life of the child with DS. Results According to the interviews, for the mothers, overall health and oral health entail specificities associated mainly with the absence of illness, the performance of daily activities, and feelings of well-being. Mothers tended to hold themselves accountable for their children’s health status. Within the situations these women experience, many of the interviewees reported difficulties in caring for their children’s oral health. Conclusions Factors linked to financial constraints, time, and access to healthcare referral services hamper the search for specialised dental care for individuals with special needs.

Key words: Oral health; Down syndrome; Qualitative research; Special needs; Disabled persons.

Introduction

In the search to encourage individuals to adopt effective preventive attitudes, health professionals require knowledge on the way people organise their health-related thoughts and actions, analysing their beliefs, attitudes, and other cognitive variables [Hallberg and Klingberg, 2005; Kaye et al., 2005; Oliveira et al., 2004; Migale et al., 2009]. It is essential for such professionals to understand that individuals’ ideas, values, and concepts on life, health, and illness are not always identical to normative thinking. Based on that realisation, the acquisition of such information makes the dental care team more aware of the population’s needs and prepared to offer adequate services [Broder et al., 2000; Newacheck et al., 2004; Fisher-Owens et al., 2007; Migale et al., 2009].

In many cases, important information is collected by dental professionals informally, during conversations with patients and their families [Hallberg and Klingberg, 2005; Oliveira et al., 2007]. All these issues play an even greater role when dental care for patients with special needs is at stake, since they display special health needs. In recent years, persons with Down syndrome (DS) have achieved greater longevity and integration into society, thereby spawning increased interest in their health [Venail et al., 2004; Allison and Lawrence, 2005; Oliveira et al., 2007]. Within this context, oral health plays a key role in the quality of life and social inclusion process for persons with DS, especially for issues related to facial harmony and dental aesthetics. Individuals with DS also display physiological and behavioural characteristics leading to increased systemic involvement and susceptibility to various dental alterations [Hennequin et al., 1999; Venail et al., 2004; Allison and Lawrence, 2005; Kaye et al., 2005; Oredugba, 2007; Oliveira et al., 2008b].

Based on this reality, careful attention to their oral health is a relevant priority, highlighting prevention as an important and efficient resource to prevent the development of diseases of the oral cavity. Nevertheless, oral health is still overlooked and/or underestimated by many family members and health professionals, as compared to other aspects involving the health and quality of life of persons with DS.

The present exploratory study adopted a qualitative approach to investigate the understanding and perceptions of a group of mothers of children and adolescents with DS on the overall health and oral health of their children and its impact on the life of the child with DS.

Materials and methods

The study adopted a qualitative method. The fieldwork was performed in a public hospital in Rio de Janeiro, Brazil. The hospital itself does not have its own oral health care. Nineteen in-depth interviews open-ended form were taped and transcribed literally (for display purposes, minor grammatical corrections were performed to make the mothers’ reports clearer). The main researcher performed all the interviews. This instrument allowed the interviewee to expound and express herself freely, but without failing to speak on the study’s central issues. The interview’s duration was left open, lasting from 20 to 40 minutes (average 25).

The study was approved by the Human Research Ethics Committee of the National School of Public Health and the Fernandes Figueira Institute, both of which belong to the Oswaldo Cruz Foundation in Rio de Janeiro, Brazil.

Research subjects

The study’s target social group consisted of mothers of...
children and adolescents with DS treated at the hospital unit. While waiting for the child’s outpatient consultation, the potential participant received an explanation on the study and was invited to participate in the interview. All the mothers agreed to participate. The interview was held in an examination room at the outpatient clinic, after the mother signed a free and informed consent form.

The sample consisted predominantly of mothers over 36 years of age (16 mothers), mostly lower-income (15). Participants were identified in the text according to their educational level (years of schooling), gender and age of the child with DS. Thus, “I.6; 8-11 years of schooling; daughter/7 years of age” was used to designate interview number 6 like a mother who had 8 to 11 years of schooling and a 7-year-old daughter with DS.

Data analysis

Given the scarcity of qualitative research on the oral health of persons with DS, this was conceived as an exploratory study on the theme. To investigate opinions, attitudes, values, and beliefs, the researcher often relies on content analysis with thematic content analysis [Bardin, 1998]. The study worked with the core themes: mothers’ perceptions concerning the health of the child with DS and mothers’ opinion on the impact of oral health on the life of the child with DS.

Results

Mothers’ perceptions concerning the health of the child with DS

- Overall health. Mothers’ assessment of their children’s health was generally positive. In the interviews as a whole, the health of the child with DS was basically associated with eating well, developing daily activities normally, not being hospitalised frequently, and only having colds. “Yes, my son is healthy. He only gets sick when he catches a cold. Aside from colds, he’s never been hospitalised (...) since he was born (...). I consider his colds normal. He eats well, sleeps well. He likes to play, likes to dance. He doesn’t have any allergies or anything.” (I.18; 4-7 years of schooling; son/4 years of age).

The quote below exemplifies some mothers’ concern for comparing the health of their child with DS to that of a ‘normal’ child. “Well, I think she’s healthy. She has her heart problem, but I haven’t seen her feel anything (...) except when she has a cold, and she gets kind of tired (...) but she plays, jumps, eats, just like a normal kid.” (I.6; 8-11 years of schooling; daughter/7 years of age).

In many cases, in the context of the child’s history, the mother perceives him or her as healthy. “She’s healthy, because she used to have pneumonia a lot. About four times (...). But now she doesn’t have it any more. She isn’t on controlled prescription medicine. She’s a girl that eats well (...). She’s a child that walks slowly (...). But I consider R. with a good health. She doesn’t get sick every day. She gets a sore throat, like normal people. Because they [persons with DS] have a really serious problem with that.” (I.5; 4-7 years of schooling; daughter/15 years of age).

Since respiratory infections are very frequent in DS during childhood and adolescence, mothers accept these illnesses as something normal for their child. “He’s healthy, doctor... He eats well (...) He isn’t a kid that catches colds all the time, although he’s allergic. When the weather changes, he gets a runny nose (...) but he rarely has to take antibiotics. He visits the doctor regularly. He’s only been hospitalised twice.” (I.7; >12 years of schooling; son/3 years of age).

- Oral health. The interviewees show a strong cultural notion that children get caries because they took (or are taking) antibiotics. “I don’t think she has a healthy mouth. Just look at her teeth, all rotten!! Lots of people say it’s cause she took too much medicine. She’s had pneumonia five times. And she took a lot of antibiotics, you know... So people say: ‘Oh, it was the medicine, she took too much and it spoiled her teeth, understand?’” (I.16; 0-3 years of schooling; daughter/9 years of age).

Although medicines targeting the paediatric population contain a large amount of sugar, in most cases the parents or guardians are not warned by the health professionals that prescribe the medication as to the need for brushing after administering the medication. This issue was observed in one of the interviews: “His teeth are like that because he took antibiotics. You couldn’t imagine how much antibiotic he’s taken this year (...). His teeth are rotten. It wasn’t until I took him to the dentist that she warned me that I should wash his mouth after he takes antibiotics, to avoid spoiling his teeth.” (I.8; >12 years of schooling; son/14 years of age).

The mothers emphasised that they sometimes overlook their child’s oral care due to the various obligations related to the child. “I do everything I can to care for his health. Go to the doctor (...) ever since he was little, I’ve never missed an appointment. I take him to the pneumologist, cardiologist, geneticist (...) you know (...) but as for the dentist (...) I let the time slip by without realising it.” (I.15; >12 years of schooling; son/4 years of age).

The interviewees showed difficulty in access to the dentist. This issue is exemplified by one of the mothers: “It’s very difficult to get a dentist for the children (...) not only with DS, but for any disabled child in treatment here (...). Because there are children that require general anaesthesia to treat or extract all the teeth at one sitting. It’s very... very... very difficult!! Very difficult to get a special dentist for the child”. I.5; 4-7 years of schooling; daughter/15 years of age).

The mothers were quite explicit about the issue of “blaming” whenever a child with DS lacked healthy teeth. “He doesn’t have healthy teeth, (...). He has cavities (...) lots of them (...) He needs to visit the dentist. Sometimes there’s so much to do that we postpone something (...) that’s why I say, I really feel to blame for some things that I postpone, that I keep leaving for later (...). I said, he needs to go to the dentist, he has to be taken to the dentist... I just took him for his clinical check-up, and now he has to be taken to the dentist, which is definitely going to be the priority!” (I.9; >12 years of schooling; son/7 years of age).

Although many mothers would obviously like to care for their children’s oral health, this does not always prove possible given their reality. “I’ve been meaning to take him for a dental check-up for a long time, but the places...
the child with DS (daughter/7 years of age). teeth when she wants to.” (I.6; 8-11 years of schooling; daughter/7 years of age).

Mothers’ opinions concerning the impact of oral health on the lives of children with DS

Problems in the oral cavity can hamper the social acceptance of the child with DS, illustrated by one of the interviewees: “It’s a problem for him in school (...) makes it harder for him to speak (...) A tooth cavity is a bother, because it causes bad breath. Nobody likes it. Not to mention a kid that drools. Lots of people think it’s really disgusting.” (I.10; 0-3 years of schooling; daughter/14 years of age).

The mothers tended to associate the impact of oral health on their children’s lives with issues related to aesthetics and halitosis. “My daughter has a lot of contact with society and needs to brush regularly and have a nice-looking mouth. Just imagine if she showed up somewhere with ugly teeth. If she had a spoiled smile, nobody would want to come near. Because kids with Down syndrome, special kids, are generally viewed poorly. A smelly mouth gives a horrible appearance.” (I.11; 8-11 years of schooling; daughter/5 years of age).

Although the mothers’ discourse highlights the importance of the mother ensuring the child’s oral hygiene, it also shows that she does not brush her daughter’s teeth regularly. “Brushing teeth four times a day!! But the main thing is brushing before going to bed. But my daughter doesn’t like to. She cries a lot. [...] And she suffers over so many other things. There are so many problems already (...). So I just let it go. I only brush her teeth when she wants to.” (I.6; 8-11 years of schooling; daughter/7 years of age).

Discussion

Mothers’ perceptions concerning the health of the child with DS

• Overall health. Representations of health are often constructed in persons’ daily lives and also mediated by professional discourse. The discourse suggests that mothers usually perceive whether their child is healthy based on prior experience as to their treatment needs. Being healthy or ill can be viewed in different ways. It is not limited to a predefined standard or model. In daily life, something that is considered normal at a given moment can become pathological at another, since the setting’s changes and demands modify what is necessary to deal with the inherent difficulties of life [Buss and Carvalho, 2007; Migale et al., 2009].

According to Canguilhem [1991], health is the capacity to be normative, that is, to institute new norms as a function of transformations imposed by reality. For children with DS, there is a social recognition that they have special needs. The society is responsible for creating adequate living conditions and decreasing barriers to a healthy life. This reaction by mothers in comparing the health of their child with DS with a “normal” child is probably related to the general population’s persistent prejudice towards DS. The stigma is still strong, and some people even feel disgusted by persons with DS.

The health team working with the social rehabilitation and integration of persons with DS needs to be sensitive to the way the family relates to the individual, in order to determine how to work with the family. It is important that the health professional show a receptive stance towards the family and the individual with DS. The caregiver needs to identify with the health professional providing care to the child, in order achieve positive results. The mothers perceive the medical history of their child as something that is part of their routine. DS is frequently associated with various systemic alterations that can complicate individuals’ health and limit their quality of life, including a high prevalence of upper respiratory tract infections, generally related to functional and structural craniofacial anomalies [Venail et al., 2004; Allison and Lawrence, 2005; Migale et al., 2009]. Other diagnoses include cardiac, gastrointestinal, neurological, and ophthalmologic disorders. Cases of diabetes, leukaemia, and hypo and hyperthyroidism can also appear over the course of their lives [Kaye et al., 2005; Hennequin et al., 1999].

• Oral health. The fact that “disease” is defined as the reflection of the association between particularities in individuals’ experience and socio-cultural situations does not mean that disease should only be considered a social construction, overlooking the biological factors acting in the process. In this context, it is appropriate to discuss the relationship between caries and use of antibiotics as displayed in the mothers’ discourse.

The over-prolonged and relatively assiduous use of medicines with a high concentration of sucrose entails a heavy cariogenic risk. Since children with DS use cough syrups frequently, they are part of a vulnerable group to the caries that requires special attention to their oral health [Pomarico et al., 2005; Oredugba, 2007].

The interviewees showed that they have to deal with various medical problems that require continuous treatment; parents of children with DS tend to postpone preventive dental care. Such behaviour usually reflects the caregiver’s lack of understanding as to the importance of oral healthcare for the individual with DS [Hennequin et al., 1999; Pomarico et al., 2005; Oredugba, 2007]. Importantly, in addition to the various obligations related to routine care of the child and other daily activities, many mothers have to deal with the difficulty of accessing dental care for special patients. Cultural factors and limited availability of time and financial resources, access to specialised health services, and health education policies, hinder the kind of care that focuses on health promotion, thus further confirming the impact of macro-determinants on oral health.

Mothers’ opinions concerning the impact of oral health on the lives of children with DS

The oral health of individuals with DS plays an important role in their social contact. Tooth decay, gingival bleeding, malocclusions, and dental trauma are identified as a
Conclusion

The most striking trait in the mothers' perception of health was their reference to absence of complications arising from DS. They associated the presence of oral health with absence of caries. Caries (tooth decay, cavities) was probably the most widely cited disease of the oral cavity, since it is the "most popular" (or prevalent) and accounts for most toothache and tooth loss.

By appropriating a discourse based on the prescriptive biomedical model still employed by many health services, the interviewees revealed a tendency to hold themselves accountable for their children's health (or lack thereof).

Acknowledgements

This study was supported by the National Council for Scientific and Technological Development (CNPq), Ministry of Science and Technology, Brazil.

References


