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**ORIGINAL ARTICLE**

# Giving low priority to oral health care. Voices from people with disabilities in a grounded theory study

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**Abstract**
***Objective.*** Our knowledge of how people with disabilities look upon oral health and dental care is limited. The aim of this study was thus to explore how the people with disabilities experience the encounter with dental health care. ***Material and Methods.*** With a focus on dental care and oral health, qualitative interviews with 16 informants with cognitive and/or physical disabilities were analysed in accordance with the qualitative method of grounded theory. ***Results.*** A core category identified and labeled "giving low priority to oral health care" was found to be related to four other categories: "being afraid of losing control", "having difficulties complying with instructions", "having a desire for continuity", and "wishing to be just like everyone else". The results show that oral health and dental care are important, but are not considered a priority by the people with disabilities. General health issues have much higher priority but do not include oral health, which consequently can affect oral health negatively. ***Conclusions.*** Of several factors identified that could be improved to make dental visits more pleasant for patients are enhancing a sense of control in the patient and improving continuity.

**Key Words:** *Communication, dentistry, disability, grounded theory, perception*

## Introduction

The number of people diagnosed with disabilities is increasing, mainly due to improvements in diagnostic skills and medical treatment. Most dental professionals are therefore likely to come across patients with disabilities or chronic medical conditions at some time during their professional career. The disabilities may influence, or even interfere, with dental treatment, but just as in the general population good dental care is essential in promoting the general health and quality of life of these patients [1,2].

In many people with disabilities, the oral cavity is affected either directly or indirectly, and the risk of impaired oral health is that much greater (see, for example, [3]). Common examples of oral health problems in these patients relate to eating, swallowing, speech and communication, chewing, drooling, esthetics, malocclusions, and poor general dental health. A learning disability (mental retardation in North America) has been reported as increasing the risk of dental health problems [4,5], problems that are even more pronounced if living conditions are poor or if access to medical and dental care is difficult [6,7].

Some of the barriers to achieving good oral health among people with disabilities are the same as for their people. The main ones are the system itself delivering dental care and the dental teams, i.e. knowledge, attitudes, and experience [8–10]. The inexperience of medical professionals in diagnosing and dealing with oral health issues could be another barrier. Medical health-care professionals have expressed this omission of oral health as naive, focusing instead on identifying the vital needs of people with disabilities [11]. Children with disabilities depend on their parents, and these families are vulnerable and highly dependent on the support and knowledge of professionals in managing their life situation; they seldom ask about dental care [12]. This, too, could be considered a barrier. It is incumbent on a grown-up with a disability to be himself responsible for getting both oral health and dental care; and not taking advantage of dental care when it is accessible is also a possible barrier to good oral health in adults.

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Odontological research has traditionally been conducted using quantitative methods. However, research methods based on questions formulated in advance, such as hypotheses, carry the risk of perspectives of individuals participating in the study not being identified or lost (the informants). There are also limitations in terms of discovering unknown but relevant and important subjective issues. Understanding this is important, particularly in new research areas, such as the perceptions of dental treatment needs and orofacial problems in patients with disabilities [13]. There is limited knowledge in the field of patients' own views on dental care, especially patients with disabilities, as most studies are based on information gained from sources other than the patients themselves. The aims of the present study were thus: (i) to explore and describe how the people with disabilities see oral health issues and (ii) to gain a deeper understanding of how people with cognitive and/or physical disabilities experience the encounter with the dental health-care system.

## Material and methods

### *Grounded theory*

The qualitative method of grounded theory was used [14–16]. This method is especially well suited to study of social processes and is intent on developing theory, model or concepts grounded in data.

### *Study group and procedure*

The study sample, comprising 16 individuals between 15 and 71 years of age (mean 44.5; SD 18.5) living in western Sweden, was strategically selected in terms of sex, age, disability, and in severity, duration, and prognosis of the disability. Congenital as well as acquired disability, and cognitive impairment as well as physical disability were included. Some informants had rare disorders, others progressive conditions, and some conditions affected facial appearance. The informants lived in their own households, by themselves, with their families, or in assisted accommodation. Some had previously lived in an institution. Two had regular jobs and university education, four were still in school (high school or university), and two had previously been working but were now receiving a disability pension. The remaining eight were either working in or had retired from special employment for people with disabilities provided by the municipality or the state. All were receiving dental care on an individual but regular basis from a general dentist, a specialist pediatric dentist, or hospital dentist. The informants were recruited through patient organizations and dental care teams.

### *Ethical considerations*

The study was approved by the Research Ethics Committee at the Faculty of Medicine, Göteborg University. Verbal and written information, including information on full confidentiality and their right to discontinue participation at any time, was given to the participants. In the case of children, or participants who needed support in their daily lives, information was also given to parents or caregivers. Written informed consent was obtained from participants. In the case of children, additional informed consent was obtained from the parents, and in the case of adults with learning disabilities from relatives/family.

### *Qualitative interviews*

A qualitative, taped interview, lasting up to 1 h, was conducted with each informant in a conversational style. The interviews were carried out by U.H. (sociologist) or G.K. (pediatric dentist) in a quiet room at the University or at the informant's home (at the discretion of the informant). The interviewer was not known to the informants in advance and had no knowledge of their dental or health-care treatments. In some cases, the daily caregiver or the parents supervised the interview.

An interview guide was used with views concerning the informant's thoughts and feelings about the meeting with dental health-care professionals, their early history of dental treatment, their thoughts and feelings during a dental examination or treatment, and their wishes regarding future oral health care. Based on these themes, the interviewer asked relevant follow-up and probing questions. During the interview, the informants were given the opportunity to raise questions of relevance to them. Data collection and analysis were conducted simultaneously up until further interviews did not provide additional information, i.e. saturation point had been reached [14].

### *Analysis of data*

The interview transcripts were analyzed by both authors in a hierarchical coding process [15], which included the use of written memos keeping track of ideas, preliminary assumptions and theoretical reflections during the analysis process [14]. At the end of the analysis, the results were discussed and validated in collaboration with external colleagues. In the open coding, substantive codes were captured and named concretely. In the next step, the axial coding process, substantive codes with similar meaning were clustered to develop categories, which were given more abstract names. Relationships between categories were sought and verified in the data. In a selective coding process, data were saturated by recoding previously assessed interviews or by new interviews. A core category, central to the data, was identified and related to all categories grounded in the data. This has been described in detail previously [10–12].

## Results

Five categories generated in the data analysis mirror the voices of people with cognitive and/or physical disabilities and reflect a deeper understanding of their encounters with the dental health-care system and viewpoints on oral health issues. A core category identified and labeled "giving low priority to oral health care" showed that the informants had restricted motivation and gave low priority to their oral health. This core category related to four other categories, namely: "being afraid of losing control", "having difficulties complying with instructions", "having a desire for continuity", and "wishing to be just like everyone else".

### *Giving low priority to oral health care*

The informants expressed restricted motivation and gave low priority to issues related to their oral health. Those with physical disabilities expressed that maintenance or improvement of physical function and mobility were issues more focused on and given more priority than oral health issues. Informants with cognitive disabilities described limited motivation and awareness of the meaning of oral health for well-being; therefore oral health issues were not highlighted. Despite this, they tried to comply with social expectations and attended the dental health clinic when requested to do so. According to the data, this core category reflects the main problem in the area studied.

> *I don't know. A long time ago I once ran away from a dentist's appointment. But now I always go to the dentist when they tell me to. In the past, I would skip dental appointments.*
>
> *There have been so many different problems. So it's always a matter of what's worst at the moment. The thing that is most difficult. That's how the priorities get set about what to deal with.*

### *Being afraid of losing control*

This category describes how informants were afraid or anxious before visiting the dental clinic. They talked about being afraid of losing control during dental treatment or check-up, and did not like dental instruments that made a noise or sprayed water. Informants with cognitive disabilities also told about being nervous about the possibility of instruments falling down their throats. Some with physical disabilities related how sitting in the dental chair caused physical pain. They would get cramp in the legs and/or their bodies would hurt owing to lying prostrate. Many of them preferred to remain in their own wheelchair during the examination and treatment. Pain from teeth or mouth was also something all informants were worried about before and during the dental appointment. They all wanted the appointment to be conducted in a calm atmosphere, and the dental professional to be gentle. They had a need to know in advance what was going to happen, and wanted information both when they came to the dentist's surgery and during treatment, often because they readily forgot what they had been told previously.

> "Informant: *A person has to be glad the dentist exists, like. But going there is no fun. Urgh.*
>
> Interviewer: *What do you think is unpleasant about it?*
>
> Informant: *It's all the stuff there, like. What are they going to do today, and what are they going to do next time, and all that. But I'm not scared of the dentist. At least I don't think I am. It's more the instruments."*
>
> *"Right, and . . . they want you to be comfortable lying down in the dentist's chair, your legs are supposed to be almost straight out. But to break the spasticity in my legs, it's better for me to keep them really bent. And when I lie there almost straight out, then . . . then my legs really start to flounder."*

### *Difficulty complying with instructions*

The informants often had difficulty complying with instructions from the dental professionals. Those with cognitive disabilities talked about difficulties understanding and in remembering to brush their teeth (and how to brush), and also in remembering not to eat after toothbrushing in the evening. If they had received other recommendations from the dental professionals, these were hard to remember and therefore often forgotten. They had no wish to inform the dental professional of their difficulty managing oral hygiene. Rather, they wanted to be "good patients" who did as they were told by the dental professionals. The informants with physical disabilities described how their lack of arm or hand strength or control made it difficult, even impossible, to comply with the instructions from the dental professionals. Most of them had special adjustable toothbrushes or other equipment to facilitate oral hygiene. Some needed help from their assistant or someone in the family. Still, all informants claimed that they really did their best to comply with the dental professional's instructions.

> *"He (the dentist) is kind of tough and firm – thinks I don't know ... I do try to brush my teeth the very best I can, and then all he does is shout at me, it seems. And I don't like that. I think it's terrible to hear. Sometimes when I have a dentist appointment I haven't had time to brush my teeth. But if I have brushed them I try not to eat, if I remember."*

### *Having a desire for continuity*

The informants related how they wanted to have the same dental health professional at every appointment, because they found it difficult and stressful to trust different or new professionals. Those with cognitive disabilities readily felt betrayed if the dental professional did and/or said something they could not understand or were not prepared for. Some of the informants just wanted to go home when they were at the dental clinic; others wanted their assistant to accompany them to the dentist. Others, still, said they preferred being treated by the nurse rather than by the dentist because they were often more familiar with the nurse. These patients claimed that they did not show fear and that they were not afraid or nervous at the dentist's; some even claimed they were afraid the professionals would not believe them. Informants with physical disabilities described how the dental professional became familiar with them and their disability, and that it was awkward to have to see a new dental professional who had to get to know all about them again from the start.

> "Informant: *I've known (name) for 17 years.*
>
> Interviewer: *Is she the dental nurse?*
>
> Informant: *That's right. And she's the only one I want, you know.*
>
> Interviewer: *She makes you feel secure?*
>
> Informant: *Yes, that's it. At least I think so."*

### *Wishing to be just like everyone else*

The informants with cognitive disabilities in the present study described how they did not want others to stare at them. They wanted to look like everyone else, to blend into the crowd; they did not like being stared at and they were afraid of negative reactions. In order not to attract attention, it was important not to be more beautiful or less good-looking than others. Most of the informants described dental or occlusal deviations as features that made them stand out from others. They were afraid their teeth were too big or too crooked. The informants with physical disabilities thought that they were even more eager for dental treatment or check-ups than people without disabilities. They seemed to be aware of their rights and could be seen as quite demanding of the dental professionals. These informants seemed to know exactly what was best for them.

> "Informant: *Well, it's important to have nice looking teeth and not to have cavities ... but that doesn't matter either if you take care of them.*
>
> Interviewer: *What do you think would happen if you didn't?*
>
> Informant: *Oh, people would stare at you. You wouldn't want to be seen. A person wants to have nice teeth and a nice face and nobody pointing and saying oh what bad teeth she has! I've heard that one. My front teeth, these, that they're big. That they are rabbit teeth."*

> *"But what I'm really trying to say is that you have to do it, learn to live with this, it's a lesson, asking for help, in that case. It's one of the lessons a disabled or functionally handicapped person has to dare to learn, because they have every right in the world to do so. And you are actually ... you have just as much ... you have to be worth the same amount of respect even if you are wheelchair bound, or ... walk crooked, or ... well, whatever's wrong with you, you deserve just as much respect. That's your human right. So it's ... and it's important."*

## Discussion

The present study provides a tentative model regarding oral health care and oral health-care priority from the perspective of people with cognitive and physical disabilities. It shows that oral health and dental care are important but not given high priority by people with disabilities. General health issues have much higher priority and oral health is not integrated within that concept. People with disabilities visit the dental health clinic, but the initiative for doing so is very much at the behest of the dental professional and the individual adjusting accordingly, albeit with low priority. This is captured in the core category *'giving low priority to oral health care'*. More responsibility is put on dental health-care professionals to reach out to people with disabilities in order to promote oral health on the same premises as for others.

The present study was conducted using grounded theory, and included informants with both cognitive and physical disabilities. There were some differences between the two groups, mainly in that those with cognitive disabilities described more difficulties interacting and communicating with the dental health-care professionals. However, all informants described the same viewpoints regarding oral health and requests for dental care. The inclusion of 16 informants was determined when data analysis reached saturation point; major efforts were made to include informants from different backgrounds. The unit of analysis in a grounded theory study is events and actions in the data rather than separate individuals *per se* [16]. The number of informants is therefore of less value than the content and quality of the data.

Oral health is often affected negatively in individuals with disabilities [3–7] and dental care and regular check-ups are important in promoting oral health. The core category, *giving low priority to oral health care*, could be identified in all four categories and included issues that probably increase the risk of oral health impairment. For obvious reasons, the medical aspects of a disability often have to be given priority by the patient, who has a high number of contacts with different professionals, including physicians, physiotherapists, psychologists, people within the social insurance and educational systems. Dental professionals, too, have to be aware of this and take account of it when planning dental treatment [17,18]. Considering all professional contacts, different treatments, medications, etc., it is understandable that preventive dental self care, even though easy to carry out, is not always delivered optimally. To promote oral health in these patients, dental health-care professionals therefore need to provide more opportunities for preventive dental care [17–19].

It is evident that the informants perceived stress related to dental care. Lack of control and fear of pain are two well-known components of dental fear and anxiety [20] and this was mentioned by several informants and included in the category *Being afraid of losing control*. There is limited knowledge concerning patients with disabilities, but there is no reason to believe that it is any less common in these patients than in others [21,22]. It is important that dental professionals are aware a person with for example a learning disability and problems cooperating with dental treatment may additionally have a dental anxiety disorder, because dental anxiety is a well-known risk factor in relation to oral health problems [23].

Many informants express low levels of self-esteem. This is shown in all categories. Low self-esteem is more pronounced in informants with cognitive disabilities. Here, the dental professional has a mission to enforce self-esteem in patients with disabilities. Furthermore, informants describe their sense of autonomy in the treatment situation as uncertain and weak. Again, this demonstrates that dental health-care professionals can learn still more and improve their communication skills [24]. According to the principle of autonomy, the patient has the right to decide on matters that concern her/him as often as possible [25]. Adequate and correct information from the dental professional as well as good communication skills are prerequisites for the patient's decision-making, which, in turn, increases their understanding of and satisfaction with dental care [26,27].

A person with a disability is often identified or looked upon as being different, even in the health-care setting. This is stress producing [12,28] and is reflected in the category *Wishing to be just like everyone else*. It is known, for example, that facial appearance affects social interaction [29]. Some of our informants appeared different to an extent that people were likely to identify them as having a disability, and possibly react in some way. The informants recognized that their dental care had to be modified to make it possible for the dental professionals to treat them. They talked about differences compared with the dental care of people without disabilities, including for example use of a lift to access the dental chair, or need for extra time during appointments to learn how to comply with treatment. Many informants also reported frequent encounters with both medical and dental health-care professionals and the difficulties having to meet new personnel when visiting health-care services. In the light of this, the category *Having a desire for continuity* is readily understandable and has previously been identified as an important supportive factor by parents of children with disabilities [12]. As each dental clinic or team usually has only a limited number of patients with disabilities and special needs, it ought to be possible to strive for better continuity for these patients. Apart from satisfying the request for continuity, this would provide the dental team with more knowledge and experience of treating people with disabilities, which is essential if high quality care is to be delivered [10].

Three previous studies carried out on oral health and disabilities [10–12] give different angles on the processes involved in providing dental care for people with disabilities, all described in tentative models. To come up with a final theory in this field, and to be able to discuss this in the light of exciting theories, a fusion of data from all four studies is needed. It is, therefore, our intention to reanalyse all data (interviews and memos) and also to be open to conducting further interviews if needed in the process of analysis.

In conclusion, the present study shows that dental care is not given high priority by people with disabilities. The load of the underlying medical condition and the numerous, related, medical and other professional contacts are among several reasons. Several factors have been identified within the dental care system that could be improved on to make dental appointments more pleasant for patients. These include reducing discomfort and pain to enhance a sense of control in the patient, improving supportive preventive care for patients with difficulty complying with self care, and improving continuity such that the patient will meet the same dental personnel with each visit and build a sound rapport with the treating team.

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