Dental health professionals' treatment of children with disabilities: a qualitative study

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As children and adolescents with disabilities may be difficult to treat, there is a risk that the disability may constitute a barrier preventing these children from receiving good odontological treatment in the same conditions as other children. *Objectives:* To describe Swedish dental care professionals' understanding and knowledge of orofacial problems and treatment needs in children with disabilities. *Methods:* In-depth interviews focusing on orofacial function, and carried out with 18 informants (dentists, dental hygienists, dental assistants), were transcribed verbatim and analysed in open and focused (selective) coding processes in accordance with grounded theory. *Results:* A core category labelled *variability in treatment* with the dimensions *professional uncertainty* and *professional commitment* emerged from the data in the analysis. Variability in treatment could be described as forming a continuum between two end-points captured in the dimensions. The dental teams' treatment of children with disabilities and their families could be placed anywhere along this continuum depending on contributing individual strategies and/or organizational conditions. *Conclusions:* The dental treatment for children with disabilities varied greatly, implying a risk for inequalities in treatment as well as in oral health. There is a need for more educational opportunities, better financing, and more support on the organizational level in order to improve odontological care for young special care patients. ☐ *Attitudes; barriers; dentistry; disability; grounded theory*

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The number of individuals with disabilities and disorders is increasing, partly due to improved medical detection (1, 2). In patients with disabilities, the oral cavity and its functions are often affected by for example problems related to eating, swallowing, speech and communication, chewing, drooling, esthetics, malocclusions, and poor general dental health (3–6). Correlations have been reported between deterioration of oral health and deterioration of general health (7), as well as between learning disabilities and impaired oral health (8–11). Many systemic conditions increase the risk of oral disease, which, in turn, is a risk factor for a number of systemic conditions (12).

There is a risk that a disability will constitute a barrier preventing the affected child from receiving good odontological treatment in the same conditions as other children (13–15). For example, there are reports of children with disabilities having increased orthodontic treatment needs, and still receiving less treatment than others (8, 9). This could be attributable to factors associated with the disability itself, e.g. impaired swallowing reflex making it hard to perform dental treatment, or to factors associated with attitudes and knowledge among dental professionals (16–19).

In Sweden, all children and youths up to the age of 19 are assured dental treatment free of charge. From a very young age (usually before the age of 3) they are offered dental examinations and full dental treatment, including specialist treatment if needed. This is offered on a regular basis and is carried out mainly within a nationwide system of Public Dental Service (PDS). However, the child patient/the family may choose a private practitioner for their general dental care on the same financial terms. Specialist treatments are mainly offered by specialized pediatric dentists and orthodontists within the PDS. This requires a referral from the general practitioner or the child's physician. Over 90% of the child/adolescent population is seen regularly by dentists. In accordance with a law passed in 1985, people with disabilities are being moved out from institutions in order to become more integrated into society. Today, children and adolescents with disabilities live at home, and the families are eligible for different kinds of support from the social insurance system. Adults with learning disabilities often live in assisted accommodation together in units of three to eight people, and with staff available day and night. In Sweden, people with disabilities often see a general dental practitioner for dental check-ups and treatments, and from this primary level of dental care may be referred for specialist treatment. The dentist's experience of treating young patients with disabilities may vary a great deal.

Living with a child with a disability is a permanent stressor for the family and affects all aspects of family life and the well-being of family members (20). It is important for these families to perceive a balance between subjective feelings of vulnerability and access to support from others, including a positive response from dentistry. In this way, self-reliance and reconciliation are developed in the parents (21). As prevention of oral diseases requires

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establishing a good rapport with these families, the dental teams need to have good knowledge and insight into the lives of families with children with disabilities. To achieve this balance, it is important to consider the whole family when treating the child with a disability. According to Scheeran et al. (22), such a family perspective leads to increased psychological and physical well-being in families with a child with disability.

Traditionally, research on oral health issues has been conducted using quantitative methods. This type of research is important for gaining objective knowledge and for the generalization of such knowledge. However, there are limitations associated with research methods based on questions formulated in advance as hypotheses. One is that the perspectives of individuals participating in the study (informants) may be lost. There are also limitations in terms of discovering unknown but relevant and important subjective issues. Such discoveries are especially important in new research areas, such as the dental health professional's perception of disability and oral health (23).

Today, there is limited knowledge about how dentists/dental personnel perceive meeting these patients or how they evaluate these patients' orofacial problems and needs. No studies have been done describing this from the perspective of the dental personnel, and in the professionals' own words. Qualitative research methods are useful in this context and may contribute to a better and deeper understanding, as these aim at exploring and describing a phenomenon from the perspective of the informants (23–25).

Using grounded theory, the aim of this study was to explore and describe Swedish dental care professionals' understanding and knowledge of orofacial problems and treatment needs in children with disabilities, and, furthermore, their perception of any special needs in the families. Knowledge about these concepts could serve as a basis for developing adequate guidelines for dental personnel regarding support for young patients with disabilities.

Materials and methods

Study group and procedure

The study sample comprised 18 dental health-care professionals from both Public Dental Service (PDS) clinics and private practices in western Sweden. In accordance with grounded theory, the study group was strategically selected in order to maximize the variations in experience in the group (24), thus all categories of dental staff were included, i.e. male and female, personnel from general dental clinics (private and PDS) and specialist clinics (pediatric dentistry and orthodontics), dentists, dental assistants and dental hygienists; different ages and lengths of professional experience were also represented. There were 10 dentists (3 men), aged 33 to 62 years, who had worked for between 5 and 36 years as dentists. Five dental assistants and 3 dental hygienists (all women) were also included, representing the same differences in age and working experience as the dentists. The first informants were recruited by contacting four general dental clinics representing different areas with different socio-economic structure, asking if they were interested in participating in the study. Information letters were then sent to the clinics and all dental professionals interested in participating were asked to return signed papers of informed consent. A time for an interview for each participant was scheduled and after the first five interviews informants were identified more strategically to ensure that all aspects of background were included.

Qualitative method

The constant comparative method for grounded theory, described by Glaser & Strauss (26) and advanced by Strauss & Corbin (27) and Charmaz (28), was used in collecting and analyzing data. This qualitative method aims at making meaning explicit by generating concepts, models or theories, grounded in empirical data. The basic principles of grounded theory include theoretical sampling and analysis, constant comparisons, theoretical sensitivity, and saturation. Theoretical sampling is used to reach saturation and is guided by the emerging categories (28). Saturation, although to some extent 'elastic', is reached when new interviews bring no additional information to the emerging categories, i.e. when new data fit within the categories already devised (28). Theoretical sensitivity is the researcher's reflexive way of developing research questions and doing analysis. Grounded theory has its roots in symbolic interactionism, and includes the idea that meaning is constructed and changes within interactions between people (29). Accordingly, perceptions of the world are individual and change constantly after interactions with it.

In qualitative research, reliability and validity are discussed in terms of 'adequacy of evidence' and 'trustworthiness'. 'Adequacy of evidence' is reached when similar relationships between phenomena emerge repeatedly from the data, while 'trustworthiness' of the developing theory is based on constant comparison. The criteria for judging the validity of a grounded theory study include fit, work, and relevance (30). Fit means that the core category is related to the salient social problem under study. A core category fits when it is relevant, works, and integrates all other concepts, making the emerging theory dense, saturated, and applicable in practice. An assumption in qualitative research is that data are generated in the interaction between researcher and informant (27, 28). The relationship between these two subjects should therefore be focused on, e.g. reflexivity (31), which contributes to the validity of the results. Reflexivity includes the idea that the researcher identifies and reflects on preconceptions brought into the study.

In-depth interviews

Open, taped interviews, lasting about one to one and a

half hours, were conducted in a conversational style with each informant. The interviews were conducted by either UH (a sociologist who has been researching in the field of both odontology and disability) or GK (a pediatric dentist), and were carried out in a quiet room at the relevant dental clinic. An interview guide including the following themes was used: the informant's meeting with a family with a child with a disability; thoughts and values affecting these children's treatment needs; his/her perception of the specific professional role. Based on these themes, the interviewer asked relevant follow-up and probing questions. The interviewer was neither a member of the clinical staff nor acquainted with the informants. During the interview, the informants had the opportunity to raise questions of relevance to them. In-depth interviews require the active and engaged involvement of both researcher and informant in responding, clarifying, and elaborating communication. Data were generated within this process, and the quality of the data was influenced by the trusting relationship between researcher and informant (32). Data collection and analysis were conducted simultaneously (26–28) and continued until new interviews did not provide additional information, i.e. until saturation was reached.

Analyses of data

The interviews were transcribed verbatim (by UH) and analyzed (by UH and GK in parallel) using hierarchical coding processes, i.e. open and focused (selective) coding (26–28). Glaser & Strauss (26) as well as Charmaz (28) describe two coding processes (open and focused coding), whereas Strauss & Corbin (27) describe three (open, axial, and selective coding). Open coding of the interview transcripts included the substance of the data being captured and segmented into substantive codes, which were labeled concretely. The codes were labeled using the informant's words, in vivo codes, or the words/concepts of the interviewers' disciplines, in vitro codes. The process of open coding led to the clustering of substantive codes with similar content into summarizing categories. These categories were given more abstract labels than the substantive codes belonging to them. In the focused (selective) coding process, categories and subcategories were saturated with additional information, assessed by new interviews or added by re-coding previously assessed data. In this process, analyses and preliminary findings were continuously discussed between UH and GK as well as with MS (nurse and senior public health researcher) as an external partner. In this process, a core category identified describing a psychosocial process was central in the data and was related to other relevant dimensions/categories found there. During the entire process of analysis, ideas, preliminary assumptions, and theoretical reflections were written down in notes or memos to keep track of the analysis (24). Finally, the interview transcripts were re-contextualized to ensure that categories were supported by the raw data, i.e. that the categories were grounded in the data. According to Charmaz (26), the unit of analysis in a grounded theory study concerns events and actions in the data rather than the separate individuals *per se*. Therefore, the number of informants is less interesting than the content and quality of the data.

Ethical considerations

The study was approved by the Research Ethics Committee at the Faculty of Medicine, Göteborg University (reference no. Ö 507-01). Verbal and written information about the study was given to the informants, including information on full confidentiality and the right to discontinue participation at any time. The informants were asked to sign a written agreement for participation in the study.

Results

In the analysis of data, one core category emerged, labeled *variability in treatment* with the dimensions *professional uncertainty* and *professional commitment*, explaining dental health professionals' different approaches to children with disabilities and their families (Fig. 1, Table 1). The variability between the two dimensions can be described as forming a continuum with the end-points *professional uncertainty* and *professional commitment*. The dental health professional's treatment of children with disabilities and their families could be placed anywhere along this continuum depending on contributing individual strategies and/or organizational conditions. There was a tendency for general practitioners to be orientated towards *professional uncertainty*, and specialists to *professional commitment*. Furthermore, four categories, related to the two end-points, emerged in the data: *managing the unknown* and a *constrained work environment* (related to *professional uncertainty*)

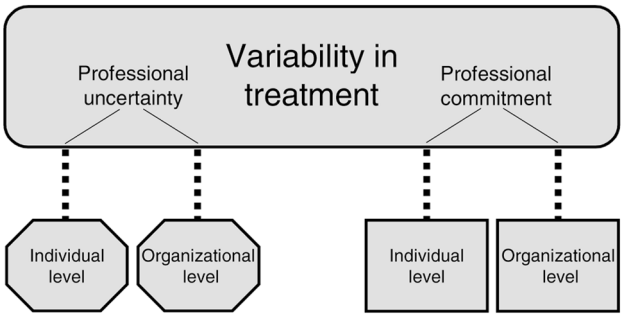

Fig. 1. Model showing the core category *variability in treatment* with its dimensions *professional uncertainty* and *professional commitment*. The core category can be described as the continuum between *professional uncertainty* and *professional commitment* and is attributable to differences on both the individual and the organizational level (represented by the quadrangles). The dimensions, categories, and subcategories are further described in Table 1.

Table 1. List of categories and subcategories of *professional uncertainty* and *professional commitment* (the two dimensions of the core category *variability in treatment*)

Dimension	Professional uncertainty	
Categories	Managing the unknown (individual level)	A constrained work environment (organizational level)
Subcategories	Normalizing the situation A cautious approach Compensatory strategies Disclaiming responsibility Keeping the parents outside	Absence of adequate guidelines Discussing our working values Lack of adequate knowledge
Dimension	Professional commitment	
Categories	Daring to face difficulties (individual level)	A tolerant work environment (organizational level)
Subcategories	Information retrieval Shouldering more responsibility Involving the parents Success against all the odds	A holistic view Encouraging interdisciplinary collaboration A tolerant workplace

and *daring to face difficulties* and a *tolerant work environment* (related to *professional commitment*) (Table 1). Each of these four categories was further elaborated by identifying their subcategories. Below, all categories and subcategories that emerged are further described and illustrated by selected quotations. The quotations are gathered from interviews with dentists, as well as dental assistants and dental hygienists.

Professional uncertainty

Professional uncertainty, identified as a dimension of the core category, describes one of the end-points of the continuum *variability in treatment*. It describes how the professional dental staff would like to have a supportive and professional approach to children with disabilities and their families, but how they are unable to do so owing to individual shortcomings and organizational conditions. *Professional uncertainty* was related to two categories labeled *managing the unknown* and *a constrained work environment*, which, in turn, were related to a number of subcategories.

Managing the unknown

At the meeting with a child with a disability and his/her family, professionals often have to face a new and unknown situation. At general dental clinics, there are more healthy patients than patients with disabilities, which means that the professionals may lack, or have considerably limited, previous experience of encountering this patient group. Limited experience may also apply in the case of some specialists who lack longer experience from special care child patients. In managing this unknown situation, the dental personnel need to use different strategies captured in five subcategories: *normalizing the situation, a cautious approach, compensatory strategies, disclaiming responsibility*, and *keeping the parents outside*, all representing the individual level of *professional uncertainty*.

Normalizing the situation. This subcategory describes how the dental professionals try to normalize children with disabilities in order to make the treatment situation more manageable. This also applies to less apparent disabilities with which they are unfamiliar, e.g. neuropsychiatric disorders such as ADHD (attention deficit hyperactivity disorder). When the informants were encouraged to describe a meeting with a child with a disability, it was primarily the children with obvious physical disabilities they thought of and talked about. A child with a physical disability is easy to recognize, but even so the informants did not ascribe any special treatment approach, because these children were assumed to have the same needs as children without disabilities. When asking probing questions during the interviews, the informants claimed that they very seldom had patients with disabilities at the dental clinic. Children with 'invisible' disabilities (e.g. neuropsychiatric disorders) were not spontaneously mentioned by the informants at all as patients at the clinic.

'Well, I can't say I think about anything specific. We treat them, I was going to say, just like we treat everybody. That's . . . a difficult question. I don't think of them as different in any special way, they're just like all the other kids.'

A cautious approach. This subcategory describes the professional dental staffs' coping strategies when they did not know, but suspected, that a child had a disability. The informants described how they monitored the child in order to 'wait and see' if something happened that disclosed a disability, and to learn more about the child's assumed disability. The following quotation from the interviews is intended to illustrate this.

'Right, what happens is . . . that things get a little difficult because . . . well you get . . . sometimes it's on the border, other time it's perfectly clear that the child is different but sometimes there are borderline cases and you have just to guess your way forward. In which case you are sure to be extra attentive to how the child is doing and what the child is saying, I mean what the child is saying to me, and I have to really listen the whole time and keep my eyes open, and figure out if my assumptions are really correct, you know. And you never want to talk to the parents about it when the child is in the room. Somehow I think it's up to the parents to bring the subject up, I guess.'

Compensatory strategies. When the informants were aware of or suspected that a child had a disability they changed their approach towards the child by taking a more tolerant and calm attitude. Procedures were allowed to take more time, e.g. 30 min instead of 15 min, without the team feeling stressed. The team explained more and moved ahead more slowly than with other children. Check-ups

would also be booked more frequently, e.g. three appointments per year rather than just one. The informants' mental preparations were awareness that the examination or treatment would last longer than it used to do.

'What I might do is set aside a slightly longer time. Maybe an extra quarter of an hour, but otherwise I don't prepare in any other way, just make a little extra time. So as to have a bit more breathing space and not have to force things.'

Disclaiming responsibility. According to the interviews, informants could reject the responsibility of treating children with disabilities. Dental assistants claimed that responsibility for the child lay mainly with the dentist, while the general practitioner's usual strategy was to try to set up one appointment, or in some cases two, and if that did not work the child was referred to a specialist pediatric dentistry clinic or for treatment under general anesthesia.

'I think you can see right away, because if things don't work out the first time, say, and then . . . if they really don't working out because of a disability, we usually get in touch with them (the special dental services) pretty quickly.'

Keeping the parents outside. At the first dental appointment, a case history was taken by asking the parents about the child's state of health and existing medication. The responsibility, according to the informants, in informing the staff about the child's disability, lay with the parents. If the parents did not mention any kind of disability, the staff did not probe further. This was done in order not to upset or embarrass the parents. The informants expressed a great deal of concern about harming or violating the parents' integrity by asking if their child suffered from any kind of disability. Many of the informants claimed that it was not their job to investigate whether or not a child had a disability. Some informants also claimed that during dental treatment they preferred to keep the parents waiting outside the treatment room, in the waiting room, so they did not disturb the examination process.

'Often things are all right when the parents are in the room, but sometimes it's easier to work if the parents aren't there. If they wait outside. Frequently it's absolutely fine, but there are also cases when it's a good idea for them to wait outside, too. Many people have . . . or at least some people have . . . some kind of assistant with them, and we have some, too, and usually that works out fine. I know there are a few children who have assistants, and when their parents come along they are much more active and less calm. Having an assistant with them instead makes things calmer. I can't tell you why.'

A constrained work environment

In order to deliver professional care to children with disabilities, dental teams need support and validation from their professional organizations: the PDS system or the corresponding network for private practitioners. The work environment was perceived by some of the informants as constrained, owing to lack of knowledge and lack of financial resources. Lack of funds led to increased feelings of stress in the informants. Three subcategories of *a constrained work environment* further describe the organization: *absence of adequate guidelines*, *discussing our working values*, and *lack of adequate knowledge*.

Absence of adequate guidelines. According to the interviews, none of the dental clinics in the study had developed special guidelines on how to deliver care or support to children with disabilities and their families. Informants described how they treated these children based on a personal feeling of what was 'the right' thing to do, i.e. intuition rather than knowledge. Some of the dental clinics, especially specialist clinics, had formed their own individual guidelines within the dental team/clinic in order to receive the children and their families in a better way or for special patient groups. However, it was at each individual informant's own discretion whether or not to use these guidelines.

Discussing our working values. None of the clinics participating in the present study had separate professional meetings or appointments for discussing the specific needs of children with disabilities. All professional meetings generally considered all patients coming to the clinic or treatment planning, and any patient within the clinic could be discussed. There were no special discussions about the treatment of or approach to patients with disabilities on an organized basis. However, from time to time such discussions were held more unofficially 'in the corridors' at the clinic or within the teams of one dentist and one assistant.

'No, we don't have any working plan, nor do we talk about it very much. Instead, each of us works on the basis of our own experience. And if there's any particular child I need to talk about, I bring it up, but we never have meetings or discussions specifically about them. There aren't all that many of them, either.'

Lack of adequate knowledge. According to the informants, dental educational programs rarely taught anything about disabilities, e.g. did not bring up the concept of disability or special needs in relation to disabilities. If disabilities were included, it was in terms of treatment and different techniques for dental treatment. Neither, according to the informants, were there educational programs provided by the clinics or the employers. The informants could only learn more about disabilities and the treatment of individuals and families by taking their own initiatives. Sometimes lectures were offered at the clinics, but attendance was voluntary.

'Well, yes, I would be happy to learn more, to go to lectures and the like, because it's really important to be able to update what you know and find out the latest information about . . . yes, that would be good to have.'

Professional commitment

Professional commitment, identified as a dimension of the core category (see Fig. 1), describes the other end-point of

the continuum, namely *variability in treatment*. This describes how dental health professionals transgress traditional limits in order to help children with disabilities and their families in the best possible way. The necessary conditions for this commitment were found on both the individual level and the organizational level and are described in two categories, labeled *daring to face difficulties* and *a tolerant work environment*. *Professional commitment* was mainly expressed at clinics, where the informants had more experience in meeting and treating children with disabilities, where they had more training and education, and better financial resources.

Daring to face difficulties

The category, *daring to face difficulties*, describes how dental health professionals dared to face the difficulties associated with treating a child with a disability and his/her family. To be able to work with these vulnerable families, it is important not to be afraid to face the difficult and hard questions in life. Children with disabilities and their families often have many difficulties, such as fatal diseases or facial abnormalities, and parents who perceive mistreatment sometimes show aggressive behavior and attitudes towards health-care professionals. This category was further elaborated with four subcategories labeled *information retrieval*, *shouldering more responsibility*, *involving the parents*, and *success against all the odds*, all representing the individual level of *professional commitment*.

Information retrieval. The informants in the present study often sought information on their own. If they were going to meet a child with a certain disability the next day, they looked for information about that disability on the Internet or in the library to be better prepared for the meeting. If they did not have the time to look for information during working hours, they did so after finishing work. The informants were also likely to talk and discuss current clinical questions with colleagues at external clinics, specialists, or more experienced colleagues, in order to gain a deeper knowledge of different kinds of disabilities.

'I begin by looking it up, of course, on PubMed or the website of the Board of Health and Welfare, to get an idea of what it's about. Then I call the parents and talk with them, and then, if there are a lot of medical complications, I ask if they would mind my phoning the child's primary physician.'

Shouldering more responsibility. The informants took increased responsibility of their own free will, e.g. they did more than they strictly needed to or were expected to according to their work assignments. These informants also tried to find flexible solutions in order to make things better for the child, such as coordinating general anesthesia with other health professionals, or giving the child special help in treatment.

'There may be children of different ages, and you group them, the little ones, the in-between ones and the big ones, to go through things and show them. They ask questions and the whole meeting, in the evening and for an hour, is very informal. One or both parents are there. The idea is kind of to make them realize that their mouths are, in fact, important, you know.'

Involving the parents. These more experienced informants were willing to include parents and to see them as a resource in deciding treatment strategies for the child. Their main interest was in working together with the parents and making them understand why different treatments were needed or were tricky for the team to carry out, or likely to be difficult for the child to cope with. Also, these informants regarded the parents as resources and requested their help in making it possible to examine and treat the child considerately. It was also important to have enough time to listen to the parents and respect their knowledge about their own child.

'Mostly listen and let them (the parents) say their piece. As we are fortunate enough to be able to follow these children and their families for many years, we enter into relationships, and I can tell you I have got to know people there in ways that have turned out to be important. The fact that we show a lot of respect for the child and the family and for their caretakers, you know. Our encounters take place very much on their terms, so to speak.'

Success against all the odds. The driving force behind individual dental health professionals working with these groups of patients seemed to be their belief in *success against all the odds*. This meant that the informants were able to successfully treat a child with disability in spite of problems related to the medical diagnosis, behavioral challenges from the child, or poor oral health status from the beginning. They reported satisfaction with their efforts in treating the patient despite individual and/or organizational shortcomings.

'We are often able to keep their oral hygiene good, in spite of having all the odds against us. I mean, they are often on lots of medication, many of them suffer from reflux, and there are all kinds of obstacles to overcome, but we still manage to keep them healthy.'

A tolerant work environment

In order to receive children with disabilities and their families properly, the work environment had to be tolerant and acknowledge new ways of working. The organization also had to be open and positive towards new working ideas initiated by the personnel. Furthermore, a sound economy was identified as an important issue in achieving this *tolerant work environment*. A clinic with too little funding led to increased stress and a poor work environment for the personnel, according to the informants. The category, representing the organizational level, was further elaborated with three subcategories labeled *a holistic view*, *encouraging interdisciplinary collaboration*, and *a tolerant workplace*.

A holistic view. Being able to see the child with a disability from a holistic perspective was also a prerequisite for good treatment. Oral health concerns not just hard

tissues, dental caries prevention, or number of teeth, the mouth can actually be a site of experiencing pleasure for the child in terms of eating or tasting. Another aspect of a disability concerns problems in everyday life. The child and his/her family may have sleepless nights, and the parents may have never-ending responsibility or are constantly struggling to receive what they perceive they are entitled to by law. This quotation illustrates a holistic view.

'That gives them a chance, too, to see the importance of the mouth to the overall health of the child. And if you have mouth problems, that can be just as significant as if you have stomach problem. They are both key elements, and if your mouth is in bad shape, that's disastrous.'

Encouraging interdisciplinary collaboration. The organization encouraged its employees to collaborate in an interdisciplinary way, mainly with other specialists, e.g. pediatricians, multidisciplinary treatment and training team (habilitation team), and psychiatrists. This interdisciplinary collaboration was easier to establish when the dental clinic was situated at a hospital. Children with disabilities frequently had general anesthesia for reasons other than dental treatment, e.g. for general health surgery. Thanks to this interdisciplinary collaboration, an awareness of oral aspects had increased and the dentists were now often called in to carry out dental treatment at the same session, since the child was being anesthetized anyway. This could also work the other way around; general anesthesia needed for dental treatment was planned so that medical examinations or minor surgery could be coordinated during the same appointment.

'We cooperate closely with the multidisciplinary treatment and training staff and others. We work together really well. If we need to anesthetize them here, we contact their physician and tell them, and ask if they need any testing done. Then we take the lab tests they need, and it all works very much to the benefit of the children and their families as well.'

A tolerant workplace. According to the interviews, the dental health professionals at tolerant workplaces felt free to try and to adopt new ways of thinking and working concerning children with disabilities and their families. Good financial resources provided more freedom of that kind and contributed significantly to flexible, permissive conditions. All dental health professionals participating in the present study described different ways of working with children with disabilities in the clinic. The main differences in working with this patient group were that certain teams had developed their own specific ways of working, and this was encouraged by the head of the clinic or the dental organization.

'A psychologist we're working with gave us an idea. Several members of the dental staff had addressed us on a new working method. It's quite unique, and the initiative came from G and myself, and we have a lot of experience with it now. It's fascinating: there were children we got nowhere with before and with whom we are now succeeding.'

Discussion

The results show that dental treatment for children with disabilities, as perceived by dental professionals, varies greatly. It can be described as a continuum running between *professional uncertainty* and *professional commitment*, and is attributable to individual differences among the dental staff and to organizational conditions. There is an obvious risk that the *variability in treatment* may lead to inequalities in oral health care for children with disabilities.

Dental health professionals within general dentistry were more likely to be situated close to the continuum end-point *professional uncertainty*, whereas specialist dental clinics were more likely to be situated close to the end-point *professional commitment*. Still, it should be pointed out that there were individual exceptions. Specialist dental clinics saw more patients with disabilities and were therefore more experienced in treating this patient group. The general dental teams wanted to serve this patient group, but their capacity was sometimes restricted because of a lack of knowledge, experience, and a constrained work environment (including restricted financial resources). According to other studies, the main barriers to equal access to dental treatment for individuals with disabilities seemed to be too few facilities and too little time (14, 33), lack of adequate knowledge and general stress related to treating this patient group (33, 34). For individuals with disabilities, the main barriers seemed to be the same as for non-disabled individuals, i.e. costs, fear, and negative attitudes to dentistry (13).

In line with the results of the present study, the findings of Bedi and colleagues (34) suggest that dental health-care professionals feel professional uncertainty in treating individuals with disabilities. Factors influencing this could be that dentists lack previous knowledge and experience in treating these patients and that there is no relevant training in either undergraduate or postgraduate programs (16–18). Furthermore, the ambivalent attitudes of dental professionals towards these patients may also contribute to less treatment being offered to these patient groups (19, 34). These previous findings provide support for the model emerging in the present study. Apparently, there are unexplored dimensions to dentists' attitudes to working with patients with disabilities, and dental teams must therefore be provided with the resources (in terms of financing, educational opportunities, and organization) to facilitate their receiving and delivering high quality dental care to people with disabilities. In a previous study where parents were interviewed regarding orofacial problems and dental treatment needs for their children with disabilities, it was found that support perceived from others (including health-care professionals and dentistry) was essential for the well-being of the families (21). These parents identified five areas perceived as the important qualities that they would like to see in dental teams: respect, involvement, continuity, knowledge, and availability. There are many similarities between these findings

and those of the present study as included in the dimensions *professional commitment*. If the level of *professional commitment* is low, there is an obvious risk that this could be one barrier preventing children and adolescents, as well as adults, with disabilities from receiving professional oral care under the same conditions as others.

According to Luterman (35), it is most important for clinicians, when counseling patients, not to be overly medical in their approach and to be open-minded towards the patients' feelings and reactions to the diagnosis and to their life situation. If the reactions of the patients are not respected, the medical counseling will be lost, since patients will be unable to handle the information given by the clinicians in a fruitful way. This, according to Luterman (35), is a violation of the patient's rights in relation to the World Health Organisation (WHO) declaration (36). Patients need and should be ensured an informed dialogue with health professionals. They also need and should have the opportunity to discuss different aspects of treatments with professionals, both dentists and other dental personnel.

Traditionally, dentists have not been part of the health planning team, and these services have therefore been absent in many health programs. Almost 40 years ago, Miller (37) reported that dental school curricula often did not include adequate experience in the management of individuals with disabilities. Today, many years later, these problems remain to be resolved. In Sweden, dental schools offer only limited teaching and training regarding approaches and support to families with children with a disability. However, specialist training in pediatric dentistry is an exception. Not only the increasing number of individuals with disabilities but also the fact that today, in Sweden, people with disabilities live their lives more openly in society instead of in institutions means that there are higher demands on doctors and dentists in terms of special medical skills to support these individuals and their families. Children with disabilities should have the right to be treated in general dental clinics if they want to, and to have the same possibilities as children without disabilities (38). But it is also important that specialist dental care, pediatric dentists in the case of children and adolescents, is provided in sufficient numbers and geographically situated near the patients in order to ensure good quality of dental care and in a longer perspective good oral health for special care patients. According to the UN Convention on the Rights of the Child (39), all children have the right to equal care and to be treated with respect for their personal needs and opinions.

In the present study, qualitative methods (grounded theory) were used to gather and analyze the data, the motivation being the shortage of reports in which dental team members' own thoughts and words had been recorded. The strength of a qualitative method is that it enables the researcher to grasp the informants' points of view in unbiased ways. In quantitative research the construction of questions or hypotheses is initially based on an existing theory, which may narrow the research topic. In oral health research, qualitative methods are helpful in improving knowledge by exploring different qualities of phenomena in areas where little is known or by gaining a fresh view on issues previously studied, that is difficult to convey with quantitative methods (40). Results from a single qualitative research study should not and cannot be generalized. The findings are applicable to people living under the same conditions and in the same cultural environment as the informants. In this study, interpretation of the results is likely to be valid for dental personnel in Sweden. However, grounded theory creates a model for understanding the concepts studied, and this model is one step in forming a theory. The first step is 'substantive theory'. However, if the model is supported by other studies it will become 'formal theory'. Grounded theory is particularly useful when there is no existing theory. Qualitative and quantitative methods may be regarded as two different tools in the research process. Depending on the type of scientific question being asked, the researcher chooses the best suited method. If it is a new area of research where the subjective meaning of a phenomenon is essential, the best tool is often qualitative research. In a next step, a theory generated from the qualitative study can be expressed as a hypothesis the researcher wants to test. In that situation the tool of choice would probably be a quantitative approach.

Historically, dental health care has been seen as an isolated part of general health care and the focus has mainly been on preventing oral disease and on the effectiveness of different dental treatments. It is hoped that a shift will take place in future dental education, with an increasing focus on the patient as a whole person, in line with the WHO declaration (36). The challenges for new dentists include the increasing numbers of patients with special needs (1, 41). The main responsibility for establishing good interaction is with the oral health-care professionals. In our opinion, oral health professionals should be given more knowledge of children with disabilities and their needs. Furthermore, oral health care should be approached jointly with general health care in order to achieve a more holistic view of the individual's physiological and psychological well-being.

In conclusion, the core category *variability in treatment* with the two dimensions *professional uncertainty* and *professional commitment* influence the oral health care for children and adolescents with disability which, in a longer perspective is likely to affect the orofacial health of these patients. In order to prevent inequalities in dental care and orofacial health it is important to:

- identify and give priority to children and adolescents with disability in dental care organizations
- allocate resources in terms of finances and dental care personnel to these patients
- take advantage of the dental staff's interest and desire to provide good support for patients with disabilities and their families by improving educational opportunities.

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