

# Facilitating Care of Children with Juvenile Idiopathic Arthritis, Orofacial Pain, and Dysfunction: An Interview Study of Specialized Health Professionals

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**Aims:** (1) To deepen knowledge on how specialized health care professionals (HCPs) reflect on encounters with children diagnosed with juvenile idiopathic arthritis (JIA) and (2) to outline a theory for orofacial care. **Methods:** Grounded theory was used to discover the psychosocial processes involved in communication between HCPs, children, and parents, and this information was used to develop a theory about these processes. Using classic grounded theory, a total of 20 interviews with HCPs were analyzed. **Results:** One main concern, “secure health and biopsychosocial development,” permeated all care. A core category was identified as “create a responsive interaction with the child and family.” The data that supported this core category helped to explain how the HCP responded to a patient to promote orofacial health. Based on the dentist’s responses to the child, eight subcategories were identified: (1) secure confidential relationships; (2) convey disease-specific knowledge; (3) communicate healthy findings and form mutual insights at examination; (4) encourage health-promoting behaviors; (5) ensure follow-up; (6) share perspectives; (7) guide parenting; and (8) improve knowledge and networks. **Conclusion:** How the dentist shall best understand the needs of a child diagnosed with JIA requires further evaluation. To promote oral health, the child must feel safe, confirmed, and supported with knowledge. Also, further studies are needed on the dentist’s collaboration with the pediatrician and the physiotherapist for contributing to overall health. *J Oral Facial Pain Headache* 2021;35:278–287. doi: 10.11607/ofph.2850

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Juvenile idiopathic arthritis (JIA) is a heterogenous disease group that includes several forms of arthritis in children with onset before 16 years of age and whose symptoms last more than 6 weeks. There are seven subgroups of JIA, with different joint engagements and prognoses. In Nordic countries, the yearly incidence of JIA is about 15 per 100,000. The treatment of JIA includes immune-modulating medication but also requires multidisciplinary care to minimize inflammation and disability.<sup>1,2</sup> Patients are encouraged to be active, and their school performance and health-related quality of life (HRQoL) trajectories are on average the same as their peers, with only mild impairments of function.<sup>3,4</sup> However, a higher pain level at enrollment is associated with less favorable HRQoL.<sup>5</sup>

Oral health-related quality of life (OHRQoL) describes the impact of oral diseases on physical functionality, psychosocial well-being, and HRQoL.<sup>6,7</sup> Temporomandibular joint (TMJ) pain in children 8 to 14 years of age who were healthy in other aspects had a significant negative impact on the global well-being domains in HRQoL.<sup>6</sup>

Compared to control individuals, TMJ pain is more prevalent in patients diagnosed with JIA.<sup>8–10</sup> In earlier qualitative interviews, it was found that children endured orofacial pain in silence, as they trusted that adults understood their situation and gave them what they needed.<sup>11</sup> However, as they grew more experienced and matured, the children gained better insight into therapies and the ability to advocate for themselves.<sup>12</sup> TMJ involvement, which is frequently associated with severe general disease, often results in diffuse local symptoms.<sup>8,13–15</sup> TMJ arthritis, lower pain thresholds, and muscular parafunctions such as clenching teeth, lip

thrust, and tongue thrust can cause varying degrees of orofacial pain, mandibular dysfunction, and alterations in facial development, conditions that contribute to complexities associated with diagnosing TMJ arthritis.<sup>13–19</sup> The TMJ is often called “the silent joint,” and it shows a low and slow grade of regeneration postarthritis. Presently, specialized follow-up and care are recommended, including interdisciplinary orofacial protocols.<sup>8,10,14,20–22</sup>

Earlier studies found that clinical examination, as well as supportive and informative patient-dentist dialogue, were most important for good outcomes.<sup>8,11,23</sup> Interviewing experienced, specialized JIA health care professionals (HCPs) about how they facilitate encounters and communicate with children about orofacial symptoms can provide important information.

The aim of this study was twofold: (1) to deepen the knowledge of how HCPs reflect on encounters with children diagnosed with JIA; and (2) to use this information to develop a theory for orofacial care of these children.

## Materials and Methods

### Grounded Theory

Data were collected and analyzed according to the principles of grounded theory (GT), an inductive qualitative method.<sup>24</sup> Classic GT views identity as being developed via interaction with others; ie, symbolic interactionism, which consists of both social actions and cognitive symbols that develop into interpersonal language.<sup>24,25</sup> Rather than testing hypotheses based on existing theory, GT seeks to discover psychosocial processes and existing problems and tries to understand how the persons involved handle these processes, thereby allowing a theory to be identified that is faithful to and illuminates the area under study.<sup>26</sup>

The present study investigated a specific domain of activity: HCPs' daily work with children diagnosed with JIA, orofacial pain, and dysfunction. Classic GT aims to generate a model that can be further tested as a hypothesis.<sup>24</sup> A modified version of GT that generates a model for proposing practical and clinical recommendations also influenced the present study.<sup>27</sup>

### Sample and Procedure

Medical and dental HCPs were recruited from eight regions in Sweden, Norway, and Finland. HCPs were purposely selected to form a heterogenous group of HCPs, all part of the specialized care chain for children diagnosed with JIA. Eligible providers received an email with information about the study. Written informed consent was obtained. Sample size is less important in qualitative research than in theoretical, quantitative research.<sup>27</sup> The sampling procedure

continued until the categories were saturated (ie, until nothing new emerged in the interviews). The final group included 20 HCPs (18 women and 2 men) with an age span between 35 and 65 years. The sample consisted of 2 orofacial pain specialists, 3 orthodontists, 3 specialists in pediatric dentistry, 1 oral radiologist, 2 maxillofacial surgeons, 1 dental hygienist, 1 dental nurse working at a specialist dental care center for pediatric dentistry, 3 pediatricians, 1 specialized contact nurse, 1 social worker, 1 physiotherapist, and 1 occupational therapist. All participants spoke one Scandinavian language fluently. All HCPs but one (the occupational therapist) had more than 10 years of experience with children diagnosed with JIA.

The Regional Ethics Review Board in Stockholm, Sweden, approved the study, and a supplement was made to include Umeå University.

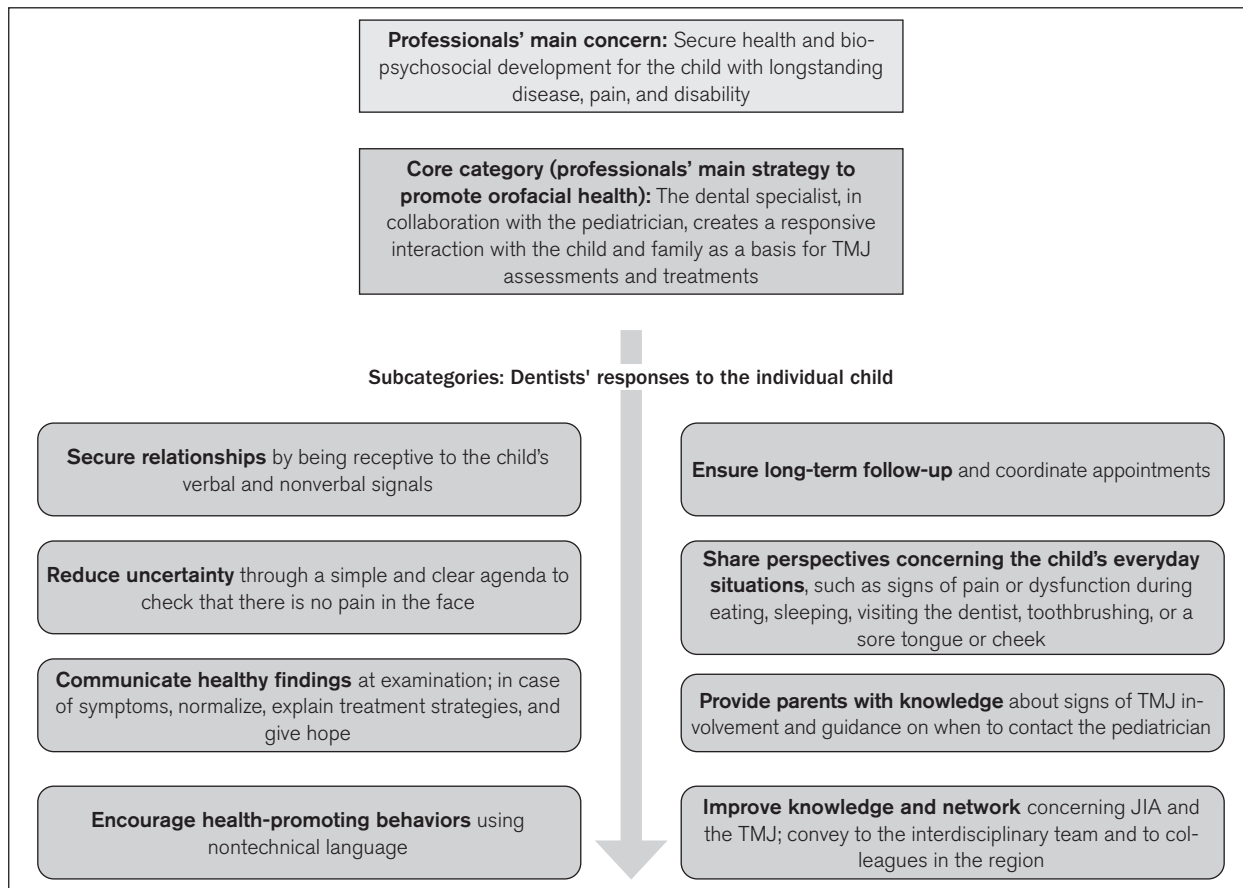
### Interviews

The first author (E.L.) interviewed the subjects—7 at their clinic and 13 via telephone—during 2018 and 2019. The interviews lasted between 22 and 90 minutes. The interviews followed an interview guide that began with the following question: “Could you tell me about your work with children diagnosed with JIA?” The informants were encouraged to speak freely. The interview guide was designed to identify barriers and facilitators in the clinical decision-making and orofacial care chains. Informants were also asked to describe how they worked to promote their patients' overall health trajectory. In addition, the informants were asked if they used specific words or special tools in their meetings with children and if these strategies changed depending on the children's age. The interview guide was revised after the first three interviews to accommodate emerging themes.<sup>28</sup> All interviews were recorded and transcribed verbatim, and no software was used to analyze the quotes and data.<sup>28</sup>

### Data Analysis

The research team included a specialist in pediatric dentistry (E.L.), two specialists in orofacial pain and jaw function (B.H-M. and M.E.), and one pediatric rheumatologist (C.E.); all were experienced in qualitative research. E.L. and B.H-M. analyzed all data, first independently and then together. The data were coded using the HCP's own words (in vivo coding). The coded data were then grouped into concepts and compared to the other interviews. The main concern of the HCP emerged when comparing codes and concepts, at which point the categories were deemed saturated. This process is known as “focused coding.” For example, to illustrate how one HCP thinks and acts:

*“ . . . you have to explain to them why they are here with me as a dentist . . . important*



**Fig 1** Study results modeling a theory for orofacial care in children diagnosed with JIA for further testing based on how specialized health care professionals think and act when communicating in their encounters concerning orofacial symptoms.

*that the first thing is not that you come to me because you have child rheumatism.”*  
 —Orofacial pain specialist

The codes that were emerging included: taking interest in the child as a person first; reflecting on the child's health and mental well-being; and taking responsibility for encounters, now and in the future. These codes in turn supported the emerging categories.

**Results**

One main concern was evident in all interviews: secure health and biopsychosocial development for the child with longstanding disease, pain, and disability. This was the same for all HCPs, medical as well as dental. Next, a core category was identified: The dental specialist team, in collaboration with the pediatric team, creates a responsive interaction with the child and family as a basis for TMJ assessments and treatments. Data supported this as the core category because it explained how the HCPs responded to a patient and how they thought and acted to promote

orofacial health. Based on the HCP's responses to the individual child, eight subcategories were identified, and the specialist dentist's knowledge and perception of the dental carer's responsibilities in the child's care chain in a clinical situation were then described in more detail (Fig 1):

1. Secure confidential relationships
2. Reduce uncertainty around TMJ involvement through a simple and clear agenda
3. Communicate healthy findings at examination; in case of symptoms, normalize and give hope
4. Encourage health-promoting behaviors using nontechnical language
5. Ensure long-term follow-up and coordinate appointments
6. Share perspectives concerning everyday situations, such as eating, sleeping, visiting the dentist, toothbrushing, or a sore tongue or cheek
7. Provide parents with knowledge about signs of TMJ involvement and guidance on when to contact the pediatrician
8. Improve knowledge and network concerning JIA and the TMJ; convey to the interdisciplinary team

### Core Category: Responsive Interactions

For the core category (The dental team in collaboration with the pediatric team creates a responsive interaction with the child and family as a basis for TMJ assessments and treatments), the children and their parents need guidance from experts to understand the causes of the symptoms and what help is available. First, however, the HCP must understand the child and the individual expression of the disease. All HCPs found it important to check the TMJ when they saw the patient.

Dentists aided the pediatrician with their assessments of the TMJ (including TMJ imaging when it was essential for decision-making) and the patient's orofacial well-being as part of the general well-being. If the dentist suspected current TMJ arthritis, this was communicated to the pediatrician, and vice versa. For treatments, the pediatrician monitored the pharmacologic protocol after assessments, and for local treatments, the agreements were different between the regions:

*"I start by asking why they come and what symptoms they have. First, I let them talk spontaneously. First, I turn to the child. . . even though they are small, they can speak for themselves. When I found out everything about the problem from the child, I turn to the parents and listen to their vision."—Pediatrician*

*". . . as signs from, for example, the eyes, face, head position, and reported habits can be so familiar to the child's surroundings that nobody has observed it until an experienced examination takes place . . ."—Pediatric dentist*

**Subcategory 1: Secure confidential relationships.** All HCPs desired to create a base of mutual confidence among the actors: the HCP, the child, and the parents. That is, all three actors should be encouraged to contribute their perspectives. Continually, they adjust to and learn from each other and plan for a long-term relationship. The disease, as well as the patient's acceptance and approach to the disease, will change through the years.

The dentists wanted the patients to perceive their care as a pleasant routine, part of everyday chores. Therefore, they set up the encounter like a regular dental consultation to count new teeth and explain jaw function.

At the first consultation, the child was usually silent, described as "in a bubble." Talking repeatedly about the disease with HCPs can be perceived as humiliating. To try to set everyone at ease and to en-

sure a purposeful relationship, it was recommended to take time to get to know the family and child by asking about, for example, interests, pets, and family outings. However, the HCP should carefully approach topics such as sports, as there is a risk that the child might feel they are being compared to others in a negative way.

The dentist sought eye contact with the child by showing interest in an item they could discuss; for example, by asking the child about a toy they were holding, or about clothes they were wearing—ie, something the child values.

*". . . some need almost no time while others require as much as possible . . . my role is to get them safe . . . this crisis processing for so long."—Specialized nurse*

**Subcategory 2: Reduce uncertainty through a simple and clear agenda.** HCPs wanted patients to cooperate and gain sufficient insight so that they could recognize disease-related symptoms. HCPs assured the patients that they were there to help them. The dentists clarified their salutogenic role in the care chain. They informed the patients to get in touch with the pediatrician first in case of symptoms from the TMJ.

The dentists described how they used their professional confidence to make patients feel safe and understand the value of the encounter. They set the terms in a way that children could accept and feel welcomed. After establishing a rapport with the child, the dentist talked with the parents for a few minutes, providing the child with an opportunity to tune into the situation and observe the interaction between their parents and the dentist. The child's anxiety level can decrease after witnessing the confident and relaxed interaction between the dentist and the parents. Subsequently, depending on response and the dentist's intention, the dentist presented a clear and simple agenda to everyone in the room. For example, the dentist might tell the child the following: "I just would like to check how nice you grow and make sure you do not have any pain in the face." Through this information, both the parents and the child will learn why the examination is important and give approval for it. However, the outcomes of an encounter with children are unpredictable. Small talk could invite the child to talk about what is on his or her mind and to suggest other courses of action. Most importantly, the dentist does not want the child (or the parents) to feel the meeting was a failure:

*". . . I inform about my role. I want them to contact the doctor only if there are problems with the TMJ."—Pediatric dentist*

**Subcategory 3: Communicate healthy findings at examination.** Analysis of the child's way of moving and palpation of the joints, associated muscles, and supporting tissues were central to identifying symptoms. Hands and eyes were the most important instruments for these assessments. After consent from the child and still with a professional open awareness, an examination can be performed. Precise questions based on the examination results can be asked in a way that the patient can answer.

Everybody in the room must be focused during the examination to be able to provide the child with adequate support if needed and to detect pain reactions. Dentists used praise to guide the child to understand how they could cooperate—for example, a dentist could compliment the child on how well they sat in the chair and opened and closed the mouth during the examination. The dentist was continuously communicating healthy findings during the examination with a calm and soft voice, explaining and informing. The importance of establishing eye contact was emphasized. Painful areas were often discovered primarily through repulsive movements and in the eyes. At signs of pain and disability, the dentist showed empathy in the facial expression. Thereafter, the child was asked if the pain was familiar. The results of the examination were explained in simple words and body language so that the child understood, then repeated and discussed with the parents.

*“. . . the child can say that everything is fine . . . maybe as he or she wish everything to be fine. . . . you must examine and interpret the symptoms, instead of words so in the eyes or in facial expressions.”—Pediatric dentist*

**Subcategory 4: Encourage health-promoting behaviors using nontechnical language.** Recovery of health is a patient's main priority. Although patients might not know what their diagnosis is, they may still have orofacial conditions that need care and follow-up. The patients may not admit they are in pain, as they have learned to live with it, assuming it as normal. This is a healthy behavior that should be supported, but such an attitude can mask the symptoms, so care must be taken when assessing a patient.

When identifying symptoms, it was emphasized to use positive words and “normalizing” the situation so that the child would not feel “diagnosed” or that there was “something wrong.” In addition, they ensured the children that painful areas and jaw dysfunction are not dangerous and that treatment can help alleviate their pain and discomfort. The dentists also encouraged self-care through the use of relaxation exercises and normal function as a basis.

Furthermore, all dentists considered it important to say something that gave the patients hope for the future. They also wanted to ensure every child that they were beautiful and growing nicely. Objectives change, and looks can be much more important for a teenager than the pain. Parents could say that they had to book appointments to the dentist for their teenager repeatedly to get confirmation that he or she was good-looking and that the jaw and face were not deformed by the disease. The dentists supported the teenagers with individually suited information; for example, by adding that the doctor's supervision and the current pharmacologic protocols are the best for the jaw. It could feel safe for the patients to hear that the dentist knows the same pediatrician, nurse, and physiotherapist that the patient knows. For example, if a headache was disclosed at the dental examination, it was good for the dentist to be able to say they both knew a professional who might be able to help.

The dental hygienist tried to capture the child's interest and to motivate by presenting the treatment as a special gift; ie, advice that would make the child even more charming, attractive, and beautiful:

*“You can get an appliance that would make your beautiful teeth look even more beautiful, this can also unload your TMJ and relieve pain.”—Pediatric dentist*

**Subcategory 5: Long-term follow-up.** Individual time intervals for follow-up at the specialist dental care center were recommended, usually annually. Disease often consumes a lot of time for the patient and family, and therefore it is important that the appointment suits their schedule. The dental nurse telephoned a parent to coordinate appointments and to ask whether they had any information the dentist should know. The referral from the pediatrician was presented as a benefit to meet a specialist as part of their care program. The dentists communicated with some of the parents before the encounter to make it easier to establish a good rapport with the child.

In the specialist network, the orofacial care could be part of the total care. The help the patient required was revealed by monitoring and learning to know the patient with time.

Collaboration with the general dentist for observations and treatments was established; for example, this meant the family would not have to travel to the specialist center to check an appliance. This referral often required telephone consultations with colleagues.

If children have been off of medication for 2 years or more, they might consider themselves as healthy and may not want to attend the specialist at the regional center. The children do not like to be remind-

ed of the disease, but can still be vulnerable to and/or have residual orofacial conditions that need follow-up. For example, if the patient visits an orthodontist or the general dentist regularly, it can be good to get in touch with them and to give advice.

*“... but you have to follow up. It is so extremely important that you follow up with a protocol, so that you can go back and look. The first time you meet the child, you may not be able to say much. When you follow up, you understand what the problems are, the disease, and what help the child needs.”—Orofacial pain specialist*

**Subcategory 6: Share perspectives concerning everyday situations.** Children living with a long-term illness need confirmation that what they are feeling is normal when they seek knowledge and help. Typically, boys and girls react differently. Moreover, with age, their behaviors, interests, and abilities change. It is difficult to generalize, but sparse contact must primarily be regarded as a lack of self-confidence in the new situation and possible treatments, as well as the burden of any further diagnoses. By trying to share perspectives and listening to the child's own beliefs and strategies concerning orofacial situations, as well as the parents' observations and examination findings, a mutual comprehension can gradually be formed. For example, the dentist can ask the child about their eating habits at home and at school. If the clinical examination disclosed a tense or strained *musculus mentalis* and *orbicularis oris*, difficulties with lip closing and messy eating may occur. Mouth opening (eg, during toothbrushing and at dental treatments) can be a problem. Questions like these can give the patients the vocabulary to express how they feel and lead to important discussions and ultimately to useful advice.

Answering questions and showing pictures of the TMJ, the tongue, and lip function can engage the child and create a good rapport. In addition, discussing how to guide tooth eruption to reduce crowding or to make an overbite smaller should help engage the child. Discussing options may rouse interest in evidence-based therapies that use appliances. It is possible that the patients already have training programs for other parts of the body, and an appliance might be easier to accept than more training programs. In this study, the HCP found that it was easier to start treatments with devices in younger children than in teenagers:

*“I work a lot with the motivation. I think it is easier to set up and get cooperation for treatment in a 6- to 7-year-old. Then you*

*avoid so much active treatment during the more difficult teenage years.”*

—Orthodontist

**Subcategory 7: Provide parents with knowledge and guidance.** Often, the bond between a parent and a sick child is stronger than the bond between a parent and a healthy child. Children, even with severe arthritis, might not receive treatment if it were not for the parents' attention and contact with the health care.

What part the parents took and the family's preferences for the encounter could change; for example, depending on the current severity of the illness or the child's maturity to take responsibility. It could also be that the child focuses on other things in life and wants their parents to take on as much as possible regarding the contacts and decisions about their care.

Gradually, the HCP recommended a two-part meeting designed for specific ages to help patients feel less exposed and therefore make it easier to create trust between the HCP and the patient. If there were questions from the parents or information that needed the parents' support, the parent joined the discussion later.

Most parents were aware of their role to be in the background of the dental consultation room and encouraged their child to respond to the dentist's questions, but some parents did most of the talking during the meetings. This strategy was meant to be helpful, and the child seemed to approve of their parents' intervention. It may also be that the parents wanted information and to have confidence in the dentist before they let a child, especially a younger one, take that responsibility. This was mutual, as the dentist found it safer to share information not only with the child but also with an adult, as the parents' perspectives were valued.

When the dentist palpated the TMJs, temples, masseter muscles, head, and neck at the extraoral examination, the parents could also notice their child's pain reactions. Then, at the intraoral examination, an age-appropriate praise such as “how nicely you opened your mouth, so I could see” is helpful even if the praise does not accurately reflect the situation. However, this praise could then lead to a more precise question that could reveal valuable information, such as “did it hurt you to open your mouth?” These interactions will help the children mature and gain confidence that they can handle the situation and understand that they are listened to. As the parents received the same information as the child at examination, they knew more about how to evaluate orofacial symptoms and when to contact the doctor. The dentists wanted to repeat the examination results in a wording appropriate for an adult, as they considered it good for both the child and the parents to hear it twice.

The HCP found that it was never wrong to encourage the children and their parents; for example, by saying that they did a good job:

*“. . . in the background, I can hear the parent supporting: what you say now does not really match what you say at home . . .”*  
—Pediatric dentist

**Subcategory 8: Improve knowledge and networks concerning JIA and the TMJ.** Determining the right therapy was complicated for all HCPs, as there were so many factors involved. Experience, working systematically as a professional, and a stable interdisciplinary teamwork were considered important. For patients with orofacial issues, each case was carefully framed, and therapy plans were monitored continuously. More extensive orofacial cases were determined using imaging, including standardized color photos. The dentists used protocols that they modified relative to the clinical picture. In addition, the patients were incredibly positive about taking part in their HCP’s research and gaining more knowledge.

A few patients required many more resources; for example, to determine the cause of orofacial pain and to alleviate the pain. In addition to treatments, these patients needed supportive contact over the years and needed to describe orofacial pain to other HCPs. Otherwise, the pain could be interpreted as a psychologic issue.

Most HCPs had worked with a different death toll than what is common today, and there has been a constant follow-up and improvement of care from all aspects. Relatively few patients came from each region, but the HCP participated in and arranged regional, national, Nordic, and international case consultations and developed guidelines, research, and specialized education, which formed the basis for this significant knowledge.

The HCP found the care chains vulnerable, and many times it seemed the care chains were about personal competence and drive.

An important obligation for all HCPs was to provide education to their colleagues in the region. Concerning dental care, it is recommended that all children, regardless of whether they have a general diagnosis or not, have an extraoral examination prior to the intraoral. It is simple and very natural for the patient that the dentist palpates the TMJ and the masseter and temporalis muscles and asks about pain before starting the intraoral examination. By doing so, the dentist learns how different children can be and how to find those that need help or referral.

A specialized dentist will meet few children with TMJ arthritis, some of whom will develop JIA. It is important that the dental professional have contacts

with the pediatricians concerning these children. There is a risk that these patients are neglected, as the general dentist might not understand or discover their problem:

*“Adults or children who do not have JIA can better describe their symptoms. You can rely more on healthy children . . . that is why it is so important to meet many children with JIA. That is when you learn as a therapist.”*—Orofacial pain specialist

## Discussion

This study explores how HCPs can improve the orofacial health of children diagnosed with JIA. The main finding was that the structure of the encounters influenced how the child and family responded to the HCP. The dentists carefully chose their words and body language to support healthy behaviors, and, instead of diagnoses, explained coping strategies and gave hope for the future. The dentists captured the child’s interest in orofacial functioning by adapting to the child’s needs and making sure the child understood what they said. In addition, the dentists were sensitive to children who needed extended care, gave them time to ask questions, followed up, and collaborated with the interdisciplinary team. They worked so that dental care could be experienced as pleasant and confirming.

These children must manage many issues related to their own disease, and they have many contacts with HCPs over a long period of time. The present study agrees with findings from the medical field; for example, that the HCP is responsible for enabling the child and parents to participate in clinical encounters.<sup>29</sup> By establishing safe relationships and routines, as well as parent support, children are encouraged to engage in communication that helps the child, the HCP’s evaluation of the child, and the parents’ understanding of their child’s symptoms and health needs.<sup>30</sup> HCPs supported the children by continuously asking for their opinion and making sure that they understood the information and what was going to happen. They tried to give the children a feeling of control over the situation and the self-confidence to ask questions.<sup>31</sup>

Children often left the decision-making to their parents and doctors. This behavior was not associated with the child’s age or gender. Typically, the children let their doctor make the decisions regarding medication strategies without protest, but often wanted to be involved in the administration of medicines, including injections.<sup>31</sup>

The HCPs based their questions on clinical examinations and observations, but before this can happen, the HCP must instill confidence by establishing a mutual understanding with the parent and a relationship with the child.<sup>29</sup> General medical practitioners working with families identify themselves as educators and providers of support.<sup>32</sup> To facilitate these roles, they establish eye contact and use a calm and soft voice.<sup>32</sup> Medical practitioners emphasize the importance of their continuous communication about what they do to keep the toddler's attention to reassure them that everything is all right and to reduce anxiety for both the child and the parents.<sup>32</sup> This is exactly what the HCPs described—it was easier for children to answer questions and express opinions related to their everyday lives when the HCP used eye contact and provided plenty of time for the children to talk about something they were interested in, such as their age or upcoming birthdays.<sup>33</sup>

For pediatric care, a questionnaire about HRQoL is used so that the children can prepare for the encounter. The HCP used the questionnaire to better understand the child's needs and to prepare for follow-ups.<sup>34</sup>

To be compliant with the child's care chain, the dentists must use a nonstandard approach. Dental care is not as demanding for the patients compared to medical care, so dentists prefer to apply a salutogenic perspective. Learning to recognize a child in pain and capture nonverbal concerns has proven challenging, and this is discussed in medical publications. Younger children may not remember past pain, but teenagers can also mask their pain, as they often do not want to admit symptoms for various reasons—for example, they do not want more treatments and investigations.<sup>29</sup>

Early diagnoses of TMJ arthritis are a challenge, and TMJ-related morbidities are common in adults with a history of JIA. There is a conceptual framework for preventive strategies that must be modified to meet and adapt to unique patient scenarios.<sup>8,9,17,20,35,36</sup> Children younger than 7 cannot provide a precise description of their symptoms and can develop severe facial growth alterations without exhibiting previous symptoms.<sup>20</sup> At a mean age of 14, more than half of these children report that symptoms from the orofacial area significantly reduce their emotional and social well-being.<sup>35</sup> Therefore, functional factors must be addressed.<sup>2,7,8,11,35–39</sup>

### Study Strengths and Limitations

While quantitative data are often restricted to exploring direct associations between predetermined and measurable variables, one of this study's strengths is its use of qualitative data, which allowed for an in-depth exploration of how HCPs adapt their behaviors. However, the present findings should be considered in the light of several limitations as well: first, the limited number of

persons and regions represented; second, the interviewer's experience as a specialist in pediatric dentistry could have affected the follow-up questions; and third, the relatively homogenous contextual factors of care are influenced by and dependent on resources, organizational structures, current attitudes, and ideologies.

The generalizability of findings might be limited by the qualitative nature of the study, and not all views may have been adequately represented due to selection bias (ie, the interviewer contacted the HCPs). To avoid this selection bias, HCPs could have been contacted by the managers of the different regions in Scandinavia, the Swedish Child Rheumatology Association, and the Swedish Dental Society.

A strength of the current study is the attempt at unconditional meetings with HCPs, which allowed for a comprehensive evaluation of various aspects of the HCPs' care for and work with orofacial symptoms according to contemporary clinical consensus guidelines for pediatric patients. Another strength is that the aggregated clinical experience was more than 300 years. The majority of the HCPs were involved in international clinical research affiliated with academic hospitals.

## Conclusions

The perspective taken of the study outlined a model for how the dentist, together with the pediatric team, can work with children diagnosed with JIA to facilitate early detection of TMJ involvement and thereby enable prevention of adverse orofacial conditions. This model—and how the dentist shall best understand the child's needs and make the child feel safe, confirmed, and supported with knowledge in order to promote orofacial health throughout life—needs further evaluation. Studies are also needed on dentist collaboration with the pediatrician and the physiotherapist for contributing to overall health.

Ensuring that these suggestions are implemented will require targeted resources and better organization.

## Highlights

- This study exemplifies clinical strategies to disclose TMJ involvement and to prevent facial pain and parafunctions for a child diagnosed with JIA from early childhood.
- This study shows the need for evidence-based methods and guidelines for orofacial health care professionals on how to think, act, and communicate to motivate children diagnosed with JIA so that their biopsychosocial development is ensured throughout their life.



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## References

- Petty RE, Laxer RM, Lindsley CB, Wedderburn L. *Textbook of Pediatric Rheumatology* [e-book]. London: Elsevier Health Sciences, 2015.
- Harrison LE, Pate JW, Richardson PA, Ickmans K, Wicksell RK, Simons LE. Best-evidence for the rehabilitation of chronic pain part 1: Pediatric pain. *J Clin Med* 2019;8:1267.
- Backström M, Tynjälä P, Aalto K, et al. Validating 10-joint juvenile arthritis disease activity score cut-offs for disease activity levels in non-systemic juvenile idiopathic arthritis. *RMD Open* 2019;5:e000888.
- Nordal E, Rypdal V, Arnstad ED, et al. Participation in school and physical education in juvenile idiopathic arthritis in a Nordic long-term cohort study. *Pediatr Rheumatol Online J* 2019;17:44.
- Arnstad ED, Rypdal V, Peltoniemi S, et al. Early self-reported pain in juvenile idiopathic arthritis as related to long-term outcomes: Results from the Nordic juvenile idiopathic arthritis cohort study. *Arthritis Care Res (Hoboken)* 2019;71:961–969.
- Barbosa TS, Gavião MB, Leme MS, Castelo PM. Oral health-related quality of life in children and preadolescents with caries, malocclusions or temporomandibular disorders. *Oral Health Prev Dent* 2016;14:389.
- Halfon N, Forrest CB, Lerner RM, Faustman EM. *Handbook of Life Course Health Development*. Cham: Springer International Publishing, 2018.
- Leksell E, Ernberg M, Magnusson B, Hedenberg-Magnusson B. Orofacial pain and dysfunction in children with juvenile idiopathic arthritis: A case-control study. *Scand J Rheumatol* 2012;41:375–378.
- Fischer J, Skeie MS, Rosendahl K, et al. Prevalence of temporomandibular disorder in children and adolescents with juvenile idiopathic arthritis - a Norwegian cross-sectional multicentre study. *BMC Oral Health* 2020;20:282.
- Glerup M, Stoustrup P, Matzen LH, et al. Long-term outcomes of temporomandibular joints in juvenile idiopathic arthritis: 17 years of followup of a Nordic juvenile idiopathic arthritis cohort. *J Rheumatol* 2020;47:730–738.
- Leksell E, Hallberg U, Magnusson B, Ernberg M, Hedenberg-Magnusson B. Perceived oral health and care of children with juvenile idiopathic arthritis: A qualitative study. *J Oral Facial Pain Headache* 2015;29:223–230.
- Stinson JN, Toomey PC, Stevens BJ, et al. Asking the experts: exploring the self-management needs of adolescents with arthritis. *Arthritis Rheum* 2008;59:65–72.
- Isola G, Perillo L, Migliorati M, et al. The impact of temporomandibular joint arthritis on functional disability and global health in patients with juvenile idiopathic arthritis. *Eur J Orthod* 2019;41:117–124.
- Bollhalder A, Patcas R, Eichenberger M, et al. Magnetic resonance imaging followup of temporomandibular joint inflammation, deformation, and mandibular growth in juvenile idiopathic arthritis patients receiving systemic treatment. *J Rheumatol* 2020;47:909–916.
- Frid P, Nordal E, Bovis F, et al. Temporomandibular joint involvement in association with quality of life, disability, and high disease activity in juvenile idiopathic arthritis. *Arthritis Care Res (Hoboken)* 2017;69:677–686.
- Skeie MS, Gil EG, Cetrelli L, et al. Oral health in children and adolescents with juvenile idiopathic arthritis - a systematic review and meta-analysis. *BMC Oral Health* 2019;19:285.
- Kjellberg H. Juvenile chronic arthritis. Dentofacial morphology, growth, mandibular function and orthodontic treatment. *Swed Dent J Suppl* 1995;109:1–56.
- Kirkhus E, Arvidsson LZ, Smith HJ, Flatø B, Hetlevik SO, Larheim TA. Disk abnormality coexists with any degree of synovial and osseous abnormality in the temporomandibular joints of children with juvenile idiopathic arthritis. *Pediatr Radiol* 2016;46:331–341.
- Valentino R, Rongo R, Alessio M, et al. "Pressure pain threshold over masticatory muscles and temporomandibular joint in patients with juvenile idiopathic arthritis". *J Oral Rehabil* 2020;47:944–950.
- Resnick CM, Frid P, Norholt SE, et al. An algorithm for management of dentofacial deformity resulting from juvenile idiopathic arthritis: Results of a multinational consensus conference. *J Oral Maxillofac Surg* 2019;77:1152.e1–1152.e33.
- Resnick CM, Dang R, Henderson LA, et al. Frequency and morbidity of temporomandibular joint involvement in adult patients with a history of juvenile idiopathic arthritis. *J Oral Maxillofac Surg* 2017;75:1191–1200.
- Stoustrup P, Resnick CM, Pedersen TK, et al. Standardizing terminology and assessment for orofacial conditions in juvenile idiopathic arthritis: International, multidisciplinary consensus-based recommendations. *J Rheumatol* 2019;46:518–522.
- Leksell E, Hallberg U, Horne A, Ernberg M, Hedenberg-Magnusson B. Parenting a child with juvenile idiopathic arthritis, orofacial pain, and dysfunction: A qualitative study. *J Oral Facial Pain Headache* 2017;31:353–361.
- Glaser BG, Strauss AL. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Aldine de Gruyter, 1967.
- Blumer H. *Symbolic Interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice-Hall, 1969.
- Dellve L. *Nordiska hälsovårdshögskolan. Coping with childhood disability [thesis]*. Göteborg: Nordic School of Public Health, 2000.
- Strauss AL, Corbin JM. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, ed 2. Thousand Oaks, CA: Sage, 1998.
- Charmaz K. Grounded theory: Objectivist and constructivist methods. In: Denzin NK, Lincoln YS (eds). *Handbook of Qualitative Research*, ed 2. Thousand Oaks, CA: Sage, 2000: 509–536.
- Lundberg V, Sandlund M, Eriksson C, Janols R, Lind T, Fjellman-Wiklund A. How children and adolescents with juvenile idiopathic arthritis participate in their healthcare: Health professionals' views. *Disabil Rehabil* 2020;1–8.
- Harder M, Söderbäck M, Ranheim A. Health care professionals' perspective on children's participation in health care situations: encounters in mutuality and alienation. *Int J Qual Stud Health Well-being* 2018;13:1555421.
- Gilljam BM, Arvidsson S, Nygren JM, Svedberg P. Promoting participation in healthcare situations for children with JIA: A grounded theory study. *Int J Qual Stud Health Well-being* 2016; 11:30518.
- Golsäter M, Johansson LO, Harder M. General practitioners' accounts of how to facilitate consultations with toddlers - an interview study. *Scand J Prim Health Care* 2017;35:3–9.
- Stivers T. Physician-child interaction: When children answer physicians' questions in routine medical encounters. *Patient Educ Couns* 2012;87:3–9.

34. Petersson C, Huus K, Åkesson K, Enskär K. Children's experiences about a structured assessment of health-related quality of life during a patient encounter. *Child Care Health Dev* 2016;42:424–432.
35. Rahimi H, Twilt M, Herlin T, et al. Orofacial symptoms and oral health-related quality of life in juvenile idiopathic arthritis: A two-year prospective observational study. *Pediatr Rheumatol Online J* 2018;16:47.
36. Bucci R, Rongo R, Amato A, Martina S, D'Anto V, Valletta R. The psychological impact of dental aesthetics in patients with juvenile idiopathic arthritis compared with healthy peers: A cross-sectional study. *Dent J (Basel)* 2019;7:98.
37. Myrlund R, Keski-Nisula K, Kerosuo H. Stability of orthodontic treatment outcomes after 1-year treatment with the eruption guidance appliance in the early mixed dentition: A follow-up study. *Angle Orthod* 2019;89:206–213.
38. Čirgić E, Kjellberg H, Hansen K, Lepp M. Adolescents' experiences of using removable functional appliances. *Orthod Craniofac Res* 2015;18:165–174.
39. Storm Mienna C, Glas L, Magnusson M, Ilgunas A, Häggman-Henrikson B, Wänman A. Patients' experiences of supervised jaw-neck exercise among patients with localized TMD pain or TMD pain associated with generalized pain. *Acta Odontol Scand* 2019;77:495–501.