

# Parenting a Child with Juvenile Idiopathic Arthritis, Orofacial Pain, and Dysfunction: A Qualitative Study

## **Eva Leksell, DDS, PhD**

Senior Consultant  
Department of Pediatric Dentistry  
Umeå University Hospital  
Umeå, Sweden

## **Ulrika Hallberg, PhD**

Associate Professor  
Nordic School of Public Health  
Göteborg, Sweden

## **AnnaCarin Horne, MD, PhD**

Postdoctoral Fellow  
Paediatric Rheumatology Unit  
Astrid Lindgren Children's Hospital  
Karolinska University Hospital  
Stockholm, Sweden

## **Malin Ernberg, DDS, PhD**

Professor  
Department of Dental Medicine  
Section for Orofacial Pain and  
Jaw Function  
Karolinska Institutet  
Huddinge, Sweden;  
Scandinavian Center for Orofacial  
Neuroscience (SCON)

## **Britt Hedenberg-Magnusson, DDS, PhD**

Associate Professor  
Department of Dental Medicine  
Section for Orofacial Pain and  
Jaw Function  
Karolinska Institutet  
Huddinge, Sweden;  
Scandinavian Center for Orofacial  
Neuroscience (SCON);  
Department of Oral Physiology  
Eastman Dental Institute  
Stockholm, Sweden

## **Correspondence to:**

Dr Eva Leksell  
Umeå University Hospital  
SE-901 85 Umeå, Sweden  
Email: eva.leksell@vll.se

©2017 by Quintessence Publishing Co Inc.

**Aims:** To deepen knowledge of how parents of children diagnosed with juvenile idiopathic arthritis (JIA) perceive the orofacial manifestations of the disease, its treatments, and their encounters with dental care providers. **Methods:** A total of 15 interviews with parents of JIA patients (3 to 16 years old) with orofacial pain were analyzed according to classic grounded theory. **Results:** The main problem was identified as controlling an unpredictable life situation that includes a child with JIA. To solve this main problem, the parent was trying to comprehend, help, and speak for the child with disability, a solution that permeated their life situation. This was therefore identified as the core category, and the other categories (ie, ways parents responded to their situation) were reflecting on and re-evaluating the life situation, monitoring the child's symptoms and treatments, adapting everyday routines, seeking doctors and information, influencing school and society, and managing job and family finances. The main problem and the various categories formed a model reflecting how parents of children diagnosed with JIA act and think. **Conclusion:** It is extremely important for caregivers to understand the complexity of the life situation for parents whose children have been diagnosed with JIA. They must facilitate the parent's understanding of how this disease can influence the orofacial area and day-to-day care. *J Oral Facial Pain Headache* 2017;31:353–361. doi: 10.11607/ofph.1689

**Keywords:** juvenile idiopathic arthritis, oral health, pain, parents, qualitative

Juvenile idiopathic arthritis (JIA) is the most common systemic inflammatory disease in children and adolescents, with an incidence of 14 in 10,000 in the Swedish population.<sup>1</sup> Disease onset most often occurs between 1 and 4 years of age or in the years directly preceding or during puberty. JIA is characterized by pain, swelling, and stiffness, with possible growth disturbances and joint destruction. Other more general impairments are pain, fatigue, and muscle weakness. Nonetheless, JIA can be invisible and difficult to diagnose because its course fluctuates, and there is no objective indicator of disease activity. Generally, JIA is diagnosed after the child has had a long-standing, noninfectious fever or when the parents contact medical services because their child does not use his/her limbs normally.<sup>1</sup> New types of medication and improved medical protocols have led to better disease control and even induced remission.<sup>1</sup>

Temporomandibular joint (TMJ) involvement in JIA produces varying degrees of orofacial pain, mandibular dysfunction, and facial dysmorphism.<sup>1</sup> Disease activities in the TMJ mainly follow general disease activity, and most condylar aberrations occur in longitudinally severe disease.<sup>2,3</sup> TMJ involvement is frequently reported at the time of diagnosis of JIA and is unpredictable: Patients diagnosed with a mild form of JIA who receive no medication and patients with more severe forms of JIA who receive pharmacologic therapy, including biologic treatment, may or may not be affected.<sup>4,5</sup> Today's improved treatments have not reduced the frequency of TMJ involvement, but have dramatically reduced the occurrence of retrognathia, which has serious effects on facial appearance.<sup>6</sup>

Temporomandibular disorders (TMD) in children and adolescents who are healthy in other respects are caused by parafunctional muscular activity leading to facial pain and headache, which can potentially

generate depression and absenteeism at school.<sup>7</sup> TMD cause pain in JIA patients far more frequently than in their healthy peers,<sup>6</sup> and medication programs do not always alleviate this kind of pain.<sup>8</sup> Because pain has a high negative impact on several aspects of the quality of life of children with JIA, early detection and prevention are essential.<sup>8–10</sup>

Studies have shown that children with JIA and orofacial pain endure in silence, focusing on learning to live with the symptoms.<sup>9,11</sup> They fight fears and sadness while trying to create a positive identity at school and with friends.<sup>12</sup> Children need supportive relations, and parents are most important in this aspect. Children need their parents to take responsibility for the disease and help them with their needs, allowing them to differentiate themselves from the disease.<sup>9,13</sup> Chewing, yawning, laughing, and performing oral hygiene are everyday experiences accompanied by orofacial pain.<sup>7,9,14,15</sup>

Parents must observe their child's daily condition, which might yield important information about the TMJ.<sup>16</sup> For example, there might be changes in the child's behavior that cause the parent to ask the child more specific questions.<sup>9</sup> Pain and/or dysfunction may be of myofascial origin or be signs of higher disease activity, requiring adjustments to the treatment approach.<sup>6,8</sup> Greater knowledge about how to inform parents about signs of TMJ involvement, coping strategies, treatment possibilities, and when to obtain medical or dental care might improve treatment outcomes.<sup>16–18</sup> Clinical examinations and discussions with professional caregivers are important forums for mutual learning and understanding, primarily through social processes such as interactions between the dentist and the child and between the dentist and the parent.<sup>18,19</sup> Asking parents to describe their child's oral health and their encounter with dental care providers might render important knowledge on how to approach parents, but this research area is relatively unexplored.<sup>13,20</sup> A child with JIA is an important stressor in a parent's everyday life; for example, both over- and underestimation of the child's feelings have been reported.<sup>21–24</sup>

The aim of this study was to deepen knowledge of how parents of children diagnosed with JIA perceive the orofacial manifestations of the disease, its treatments, and their encounters with dental care providers.

## Materials and Methods

### Grounded Theory

Data were collected and analyzed according to the principles of grounded theory (GT), an inductive qualitative method.<sup>25</sup> In the context of the present

study (a family with a child who had TMJ arthralgia, muscular pain, and dysfunction), the aim was two-fold: to discover parents' perceptions of their reality and to understand their behavior as a result of this situation. Classic GT views identity as being developed in interaction with others; ie, symbolic interactionism, which consists of both social actions and cognitive symbols that develop into interpersonal language.<sup>25,26</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 them, thereby allowing a theory to be identified that is faithful to and illuminates the area under study.<sup>27</sup> The present study investigated a specific domain of activity: the daily life of parents with a child with orofacial problems and special care needs. Classic GT aims to generate a model that can be further tested as a hypothesis.<sup>25</sup> A modified version of GT that generates a model for proposing practical and clinical recommendations also influenced the present study.<sup>28</sup>

### Sample and Procedure

Parents of children diagnosed with JIA were purposely selected in order to form a heterogenous group that varied in disease presentation, duration, age, sex, and social and family situations. Eligible parents received an informative letter asking if they wished to participate, and written informed consent was obtained from all participants. Their children (aged 3 to 18 years, 11 girls and 4 boys) were diagnosed with JIA, and all but three were referred to the specialist dental care for children at the Eastman Dental Institute in Stockholm or at Blekinge Hospital in Karlskrona, Sweden. The children were examined according to the Research Diagnostic Criteria for TMD (RDC/TMD) within 6 months before the interview.<sup>29</sup> Three patients were diagnosed with erosions on the condyle by the specialized dental care and thereafter referred for specialized medical care. Only parents of children diagnosed with JIA according to the International League of Associations for Rheumatology (ILAR) and attending specialized medical care at Astrid Lindgrens Childrens Hospital, Karolinska University Hospital in Stockholm or at the specialized medical care for children at Blekinge Hospital in Karlskrona were included in the study.<sup>1</sup>

Sample size is less important in qualitative research than in theoretical, quantitative research<sup>28</sup>; thus, the sampling procedure continued until the categories were saturated (ie, until nothing new emerged in the interviews). Three families refused to participate, two without explanation and one with the explanation that the disease consumed so much time already. The final group was comprised of 15 parents with a female to male ratio of 11 to 4. Parents were

aged 30 to 46 years. Eleven of the parents were either married or living together with the other parent. Their children had been diagnosed with JIA since 1 to 12 years of age and were taking no medication (one child), a nonsteroidal anti-inflammatory drug (NSAID) (four children), low-dose methotrexate (five children), or etanercept (seven children). The orofacial problems that the children experienced ranged from no problems to severe pain and dysfunction or problems with looks because of crowding of teeth, prominent horizontal overbite, or small jaws. Families spoke Swedish fluently (two families spoke two languages at their home). Half of the families were living in a rural area of Sweden (county of Blekinge), and the other half in the Stockholm city area. Six children had taken part in an earlier qualitative study,<sup>9</sup> and eight were patients of the first author (E.L.). Parents were notified that they had been recruited on the basis of their child's JIA diagnosis, oral health status, and sociodemographic factors. The Regional Ethics Review Board in Stockholm, Sweden approved the study, and a supplement was made to include parents of JIA children in Blekinge.

### Qualitative Interviews

The first author (E.L.) tape recorded interviews in the subjects' homes or at the clinic, and one subject was interviewed on the telephone. The interviews lasted up to 90 minutes. The interviewer introduced herself as a dentist with a special interest in learning more about children with JIA and their families and began the interview by asking "Could you tell me about a good day?" The informants were encouraged to speak freely using their own words. The interviewer asked open-ended, probing questions and referred to an interview guide that listed areas of interest, including questions about the parent's perceived relations with the child and the child's jaw function, pain, treatments, oral hygiene, and eating. The questions were also designed to elicit what professional support the parent thought they needed to promote their child's oral health. The interview guide was revised after the first three interviews to accommodate emerging themes.<sup>30</sup> Each interview was transcribed verbatim, and no software was used to analyze the quotes and data.<sup>30</sup> A native English speaker translated the quotes into English.

### Data Analysis

The research team included a specialist in pediatric dentistry (E.L.) who was also experienced in qualitative methodology, two specialists in orofacial pain and function (B.H.M. and M.E.) who also had some experience in qualitative research, a pediatric rheumatologist (B.H.M.), and a sociologist with vast experience in qualitative methodology (U.H.). E.L. made

the first taped interview, which was then read and commented on by U.H. E.L. and U.H. began by analyzing the data independently, using an open coding process and reading the interview line by line, posing the question: "What does the parent tell us about his/her perspective?" E.L. and U.H. then coded the data using the parent's own words (in vivo coding), if possible. After reading the codes and comparing them with each other, E.L. and U.H. grouped them into concepts. New interviews were coded in the same way and compared with the other interviews. By comparing codes and concepts back and forth, a main concern was found, and categories were determined to be saturated. This process is known as focused coding. For example, the quotation below illustrates how one parent thinks and acts:

*"There is a lot of planning that parents need to help the child with . . . structure and routines I think are good . . . you cannot always wait with things concerning school while other things can wait. Learn to listen to . . . to the body of the child. To do as much as possible and then rest."*

The codes that were emerging included worries; monitoring the child's health; reflecting over the child's health, well-being, and schooling; and taking responsibility. These codes in turn supported the following emerging categories: trying to comprehend, help, and speak for the child with disability; reflecting on and re-evaluating life situation; monitoring the child's symptoms and treatments; and adapting daily routines.

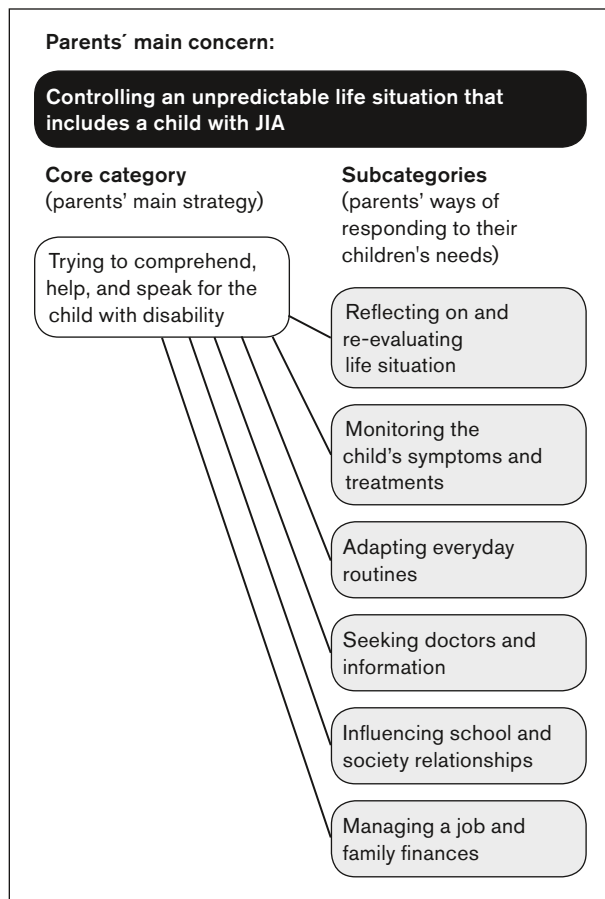
Memos were written to record and track the process throughout the analysis.

## Results

Parents thought that their situation needed attention, and the interview was an opportunity for this. Therefore, parents needed to be free to speak, and they could tell the interviewer that they did not want the child to hear how tough the parent's experience of their everyday life could be.

The interviews that included both parent and child at their home took place after a meeting involving both of them in their kitchen or living room. Parents were overhearing the interview with the child, but were asked not to interfere. In a few cases, the parent was interviewed just after the child. To have the interview in a room separated from the home or the clinic was preferred, but could not always be arranged.

Parents' main concern regarding their children's orofacial manifestations of JIA, its treatments, and



**Fig 1** Study results modeling how parents of children diagnosed with JIA think and act regarding the child's oral health and encounters with dental professionals.

their encounters with dental care providers was identified as controlling an unpredictable life situation that includes a child with JIA. Data supported this as the main concern because it explained the parent's behavior; ie, their worries and responsibilities for their child's health permeated their life situation. The parents used several strategies to address this main concern: They were reflecting on and re-evaluating their life situations, monitoring their child's symptoms and treatments, adapting everyday routines, seeking doctors and information, influencing school and society, and managing a job and family finances. These strategies represent the categories in this study. The core category for coping strategies was trying to comprehend, help, and speak for the child with disability because it was a component of all coping strategies; ie, in all the coping strategies (categories), the parents took responsibility for their child (Fig 1).

### **Core Category: Trying to Comprehend, Help, and Speak for the Child with Disability**

Parents trying to comprehend, help, and speak for their child's health at home and in all situations, including meetings with teachers, youth recreation leaders, health care providers, and encounters with friends and relatives, permeated all categories. Parents experienced their child as being exposed, not like other children, and needing the parent's wider perspective and authority as an adult to comprehend, help, and advocate in all situations. Parents felt that the child was unable to explain the consequences of the disease to adults who did not understand, possibly because the child had forgotten what being healthy could be like.

Parents felt that the child needed them for planning their everyday lives and futures. Typical problems concerning the orofacial area could be how to adapt to food at the school cafeteria and what tooth brushing tools were suitable. Parents felt that they always had to be there for their child to offer guidance on physical activities, on planning the child's life, and when to seek health care.

Parents always felt troublesome when they met with others. They felt that neither school professionals nor health professionals listened fully to them or understood the consequences of what they said. Parents explained that they preferred to talk about how well the child was and the things he/she could do instead of speaking about problems, especially in front of the child, but this was seldom possible.

For example:

*"We went to the dentist and asked them why it was like a hole between his teeth so that he couldn't bite. I felt like they thought I was a troublesome mother. Time passes by and it is as if nobody listens. Not before we were referred to the specialist did he get a correct diagnosis and a referral to the pediatric medical care. It took two years, such a long time, which is frustrating."*

*"His medication did gradually not have full effect after a period of time. Now he has another (medication) but I do not know whether it is the same situation now."*

#### **Subcategory 1: Reflecting on and Re-evaluating Life Situation**

Most parents had to reflect on and re-evaluate what was important in their lives. Maintaining the family's cohesiveness and happiness on days when the family members were healthy had become very important. Other parents, however, claimed that the day-to-day struggle had been one of the reasons for divorce.



Some parents were depressed or had depressive feelings about needing to stay home to comfort and care for the child so much. Some parents were unable to work or socialize to the extent they would like and received little understanding at their work, at school, or in society. Others found comfort in their religion.

All parents felt that their child needed them to take responsibility as much as possible for their disease. Parents would express this as “we have it (the disease) together” or “we are so close.” Some parents were more rational: “take each day as it comes, and do the best.” Some even neglected the experience of struggle: “no problem, it is just to do the best.” Parents could also be more resigned, saying “it is as it is . . . what can I do?” or did not appear to reflect (“I feel like anybody else”). A few parents reported that they had so many problems (for example, with diseased relatives) that they had little time or energy left for the child with the “minor” disease of JIA.

Parents explained that they had difficulties relaxing if the child did not feel well. They were constantly worried that the disease could become worse or increase the child’s pain.

Parents mentioned that they also needed structure for their own lives and that they had to protect their own integrity; for example, by letting the other parent, other relatives, or the child take responsibility. Parents could experience this as more or less of a problem. A few parents suffered from their child’s everyday pain and care, as it was making their own lives unreasonably chaotic.

All parents were very proud of their child for being so healthy and active despite the disease.

For example:

*“We have become very close in our family as we have learned to be thankful and happy for every day we are healthy. Our friends are used to us being unpredictable. We cannot book any activity for sure because something is always happening with one of our children’s health, which makes it impossible to come.”*

### **Subcategory 2: Monitoring their Child’s Symptoms and Treatments**

To be able to give proper attention to a fluctuating disease and assist the child in treatments, the development of a fruitful communication between parent and child was considered important. Several parents mentioned that they had an eye on the child’s behaviors for monitoring degree of pain; for example, when the 1- or 2-year-old child did not take steps as the child normally did, this was interpreted as increased pain and disease activity. Some parents said that they had difficulties discerning how their child felt or

what was wrong, while others stated that their child was able to communicate about pain in different ways from a young age.

Monitoring their child’s current mood was how parents were best able to discern the child’s symptoms at all ages. The child’s condition could change in just a few hours because of a suddenly swollen joint or a bout of pain and tiredness. A change in mood or avoidance of activities and friends signaled that pain was more intense. Other symptoms were tears, requests for analgesics, or simply a change in the eyes. In this respect, orofacial symptoms and general symptoms were the same, but other behavior-related changes that the parents noticed, such as the child not wanting to eat chewy food or not being able to open his/her mouth very wide, indicated orofacial involvement.

Administering medication, pills, and injections was sometimes difficult and consumed time and energy. Some children occasionally—or for longer periods—refused to take their medication, although most felt much better with medication and therefore understood its importance. One mother said that her child took the medication without any problem only once a year, as a birthday gift (to the parent on the parent’s birthday).

Parents could also have trouble getting the child to visit health care providers. There could be evenings, days, and even weekends when the child screamed from pain and needed their parents’ help to manage it (for example, with hot bandages, massage, and analgesics); yet, when meeting others, even the doctor, the child could say that everything was good. According to the parents, children could worry and be afraid of facial disfigurement or becoming more diseased or crippled. This was something the parents had to address, provide information about, comfort, and take care of in various ways. Giving the child the right amount of care without overprotecting the child was a crucial subject that parents always considered.

Parents were always working to help their children assume responsibility for the disease, something that caregivers reinforced (for example, by speaking directly to the child during clinic visits).

For example:

*“I didn’t know that he had headaches every day and I didn’t reflect over why he only wanted yoghurt and not real food before we came to specialized dental care.”*

### **Subcategory 3: Adapting Everyday Routines**

Parents were keen on trying not to let the disease rule their life. Still, considerations of the diseased child had a great influence on everyday life. Monitoring the child’s health in the morning before the child left for

school or daycare and being prepared to stay at home if needed was one important routine. Routines for taking medications, such as weekly injections (at home or at the hospital) or daily pills, were another. Monitoring tooth brushing during periods of jaw pain, serving food that did not need to be chewed, and looking after the child's occlusal appliance and encouraging its use were the responsibilities of the parent.

For example:

*"When she cannot chew I have to come up with good alternatives. When she goes to a party with her friends I send food with her!"*

#### **Subcategory 4: Seeking Doctors and Information**

Parents were interested in learning more about the disease and available pharmacologic treatments. They were always looking for more information. Meeting health care providers was most important for gaining information about how the disease expressed itself for the individual child and how to interpret its signs and symptoms.

Some parents reported they had suspected jaw involvement, but did not know where to go for this: to the ear, nose, and throat doctor, to the Health Center, to the emergency clinic, or to the dentist. Many parents expressed frustration over the difficulties of finding a dental caregiver for the jaw problems associated with the disease.

Meeting a new caregiver was considered threatening, as most parents could describe meetings that had been more or less catastrophic. To point out diagnoses and disabilities required a caregiver with the interest and ability to listen to both the parent and the child. Poor or failed social interaction between the child and caregiver could make the situation worse for the child and the family.

For example:

*"We are really thankful for the information we got from the dentist. It has been really helpful for us. L is very worried, as she is reading catastrophic information on the internet about her disease. When we are alone at home, she cries and tells me that she is so afraid, but when she meets others, also her caregivers, she is more moderate. I have to call dental caregivers and make appointments for advice."*

#### **Subcategory 5: Influencing School and Society**

The child's healthy appearance and reluctance to talk about pain or disease made it difficult for the parent to explain their situation and also influenced the help that society was willing to give them. The fluctuating nature of the disease made it difficult for the teach-

ers to comprehend what was normal for the child; for example, the child could stay home from school one day, need special food or a wheelchair another day, and function normally the third day.

In the parents' experience, school professionals needed hands-on instructions, and the parents always had to follow up and check that the child got what was needed.

Adults pay for their dental care in Sweden, including occlusal appliances and periodontal care, which parents considered unfair.

For example:

*"When he gets older, he has to pay for both TMJ and periodontal treatments, problems that are caused by the disease. I do not think this is right."*

#### **Subcategory 6: Managing a Job and Family Finances**

Parents were forced to consider their child's disease when deciding a job, career opportunities, housing, and holidays. There could also be personal problems, other diseased children in the family, a diseased parent, or other relatives in need of help and support. Some parents experienced lack of understanding from their employer or had a job that made it difficult to take sick leave.

For example:

*"Neither I nor my husband has been able to have the careers that we expected because of all the appointments at the doctor, the physiotherapist, the dentist, the occupational therapist, meetings at school, and so on."*

## **Discussion**

The present study found that pain and dysfunction in the orofacial area for a child diagnosed with JIA affected the everyday lives of not only the child, but also the parent and the family.

Parents strived to control an unpredictable life situation with varying degrees of success. For some, life was chaotic. The present study showed that parents need professional help that not only understands the nature of their child's disease and treatment but also understands the family's situation. Because the parents play a significant role in their child's well-being, this study asked parents to give their opinions about limitations and opportunities for professional support to promote the child's oral health. This showed that the ability to listen to, involve, and interact with the parent was essential for the care of the child and facilitated life for the whole family.

The results stress that parents need caregivers to assist in explaining symptoms to the child in a supportive manner, using words that the child can understand with a focus on treatments, coping strategies, and hope for the future. The findings suggest that dental caregivers need to design holistic, parent- and patient-focused treatment strategies that are individually tailored starting from the time of the child's diagnosis.<sup>16,31,32</sup>

The participants reported a vast variation of insecure and unpredictable life situations, of not being understood, and of a lack of compassion from others.<sup>16,21,23</sup> These difficulties have been described in earlier literature on JIA and pain, but not with regard to the orofacial area for parents with a child diagnosed with JIA.<sup>33</sup>

Parenting a child with JIA requires a certain amount of overprotection and should be supported.<sup>34</sup> However, this is difficult with an unpredictable disease, and the parent must learn to comprehend, listen to, or interpret the child's signals.

Studies have shown that not even a parent can know exactly what their child feels; the child has to, step by step, learn to take their own responsibility and to communicate with caregivers, starting from the day of diagnosis.<sup>34</sup> Caregivers need to be able to listen to the parents, view the child as an individual of a certain age, and ask adequate questions.<sup>34</sup>

Pain and tiredness in JIA are individual experiences and difficult to measure. Since the child with JIA mostly "looks healthy," these children are different from other special care children, and improved knowledge is required. As a child with JIA may not know what it is to be "normal" or "healthy," the experience that the child obtains with age is valuable, and an older child is indisputably more "reliable" than a younger child. As the child grows older, the parents should let the child gradually take over responsibility for the disease.<sup>34</sup>

The very close relationship between the children and the parents that emerged in the interviews was usually viewed as a positive effect of the disease. For example, there were fewer conflicts during the teenage period when children tend to rebel against their parents and other authorities, maybe because the children understood how dependent they were on their parents. Parents who succeeded in taking control, who were able to let their child take the right amount of responsibility, and who did not let the child control their own lives and those of their family when they were still too young to do so were the best functioning and felt mentally best.

Caregivers must build trust and form relationships with the child and with the parents in order to take a case history and have a fruitful dialogue with mutual insight into what is important concerning orofacial

symptoms.<sup>13,35</sup> Because the parents may have a complicated life situation and find it difficult to understand what the child is experiencing (eg, the intensity of the pain and where it originates), a responsive, informative, and supportive attitude on the part of the caregiver toward the parents and the child is important, together with a clinical examination of the child at a specialist clinic.<sup>6,9,14</sup> This is in accordance with today's recommendations, as it may contribute significantly to treatment decisions and to improving patient care.<sup>34,36</sup>

While quantitative data is 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 in-depth exploration of the indirect process involved in the adoption of behaviors. However, the present findings should be considered in the light of some limitations as well. First, the fact that the child and parent were first interviewed in one another's presence can be questioned, as information could have been transmitted from one informant to another. Telephone interviews would be a way to avoid this in future studies. In addition, the generalizability of findings might be limited by the qualitative nature of the study. Not all views may have been adequately represented due to selection bias: for example, those of parents who did not experience an adequate sense of coherence with the Swedish society's health care system. This study may also have been comprised of more parents of children with a severe form of the disease or with, to date, difficulties in controlling disease activity and pain,<sup>21,35</sup> as jaw problems are often connected to a more severe form of JIA. The parents with a strained situation needed to speak the most, which might give the impression that this study was focusing on them. To avoid this selection bias, parents could have been contacted through the National Association for Patients with Rheumatic Diseases, newspapers, or social media. There may be parents with an overwhelming number of their own problems or with narcissistic tendencies (in other words, parents who lacked the capacity and energy to understand their child) who did not participate.<sup>11,24</sup>

A strength of this study was the attempt at unconditional meetings with the parents, which allowed a comprehensive evaluation of various aspects of orofacial symptoms according to contemporary clinical consensus guidelines on pain assessment in pediatric patients.<sup>37</sup> More research is necessary to elucidate children's pain behavior and parents' interactions with children and caregivers concerning symptoms in the orofacial area. Parenting and dental professional care for children with special needs is different in several aspects. More research and education are needed on how to be a parent and a caregiver for children suffering from orofacial pain, as well as more knowledge

and guidelines on how the dental and medical services collaborate for the best outcome. Hypothesis-based research could, for example, compare different structures of the professional meeting with the family, the parents, and the child at different ages. Adequate questions for facilitating early diagnoses would be an important subject. Hypothesis-based studies within dental care on management of children with JIA could provide more structured attention and guidelines. There should also be more studies exploring the interactions of parents and children that also include the caregivers' perspectives. Adequate information on the internet would also be useful to recommend for patients of different ages as a complement to professional meetings.

## Conclusions

For parents with a child diagnosed with JIA, the present results emphasize how important it is for caregivers to listen and to show empathy and interest in the parent's situation, to ask precise questions when taking case histories in order to make it easier for parents to understand the area of interest, to provide individually tailored psychosocial support and suggest positive coping strategies, to explain and provide treatments, and, finally, to give hope for the future. Awareness of both the parent's and the child's social interactions with health professionals and of how to approach a parent with a child with longstanding illness and pain is crucial for disclosing and treating these children's orofacial symptoms.

## Acknowledgments

This paper was written with support from Blekinge County Council and the Stockholm Public Health Care Service. Financial support is gratefully acknowledged from the Swedish Rheumatism Association (R-228771). The authors also thank Gail Conrod, English language consultant. The authors report no conflicts of interest.

## References

- Cassidy JT, Petty R, Laxer R, Lindlsey C (eds). *Textbook of Pediatric Rheumatology*, ed 6. Philadelphia: Saunders, 2010.
- Cedströmer AL, Ahlqwist M, Andlin-Sobocki A, Berntson L, Hedenberg-Magnusson B, Dahlström L. Temporomandibular condylar alterations in juvenile idiopathic arthritis most common in longitudinally severe disease despite medical treatment. *Pediatr Rheumatol Online J* 2014;12:43.
- 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.
- Keller H, Müller LM, Markic G, Schraner T, Kellenberger CJ, Saurenmann RK. Is early TMJ involvement in children with juvenile idiopathic arthritis clinically detectable? Clinical examination of the TMJ in comparison with contrast enhanced MRI in patients with juvenile idiopathic arthritis. *Pediatr Rheumatol Online J* 2015;13:56.
- Kristensen KD, Stoustrup P, Küseler A, Pedersen TK, Twilt M, Herlin T. Clinical predictors of temporomandibular joint arthritis in juvenile idiopathic arthritis: A systematic literature review. *Semin Arthritis Rheum* 2016;45:717–732.
- 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.
- Nilsson IM, Drangsholt M, List T. Impact of temporomandibular disorder pain in adolescents: Differences by age and gender. *J Orofac Pain* 2009;23:115–122.
- Bromberg MH, Schechter NL, Nurko S, Zempsky WT, Schanberg LE. Persistent pain in chronically ill children without detectable disease activity. *Pain Manag* 2014;4:211–219.
- 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.
- Barbosa TS, Castelo PM, Leme MS, Gavião MB. Associations between oral health-related quality of life and emotional statuses in children and preadolescents. *Oral Dis* 2012;18:639–647.
- Mienna CS, Johansson EE, Wänman A. "Grin(d) and bear it": Narratives from Sami women with and without temporomandibular disorders. A qualitative study. *J Oral Facial Pain Headache* 2014;28:243–251.
- Tong A, Jones J, Craig JC, Singh-Grewal D. Children's experiences of living with juvenile idiopathic arthritis: A thematic synthesis of qualitative studies. *Arthritis Care Res (Hoboken)* 2012;64:1392–1404.
- Duijster D, de Jong-Lenters M, Verrips E, van Loveren C. Establishing oral health promoting behaviours in children—Parents' views on barriers, facilitators and professional support: A qualitative study. *BMC Oral Health* 2015;15:157.
- Leksell E, Ernberg M, Magnusson B, Hedenberg-Magnusson B. Intraoral condition in children with juvenile idiopathic arthritis compared to controls. *Int J Paediatr Dent* 2008;18:423–433.
- Sällfors C, Hallberg LR, Fasth A. Gender and age differences in pain, coping and health status among children with chronic arthritis. *Clin Exp Rheumatol* 2003;21:785–793.
- Connelly M, Anthony KK, Schanberg LE. Parent perceptions of child vulnerability are associated with functioning and health care use in children with chronic pain. *J Pain Symptom Manag* 2012;43:953–960.
- Filocamo G, Consolaro A, Schiappapietra B, et al. A new approach to clinical care of juvenile idiopathic arthritis: The Juvenile Arthritis Multidimensional Assessment Report. *J Rheumatol* 2011;38:938–953.
- Consolaro A, Ravelli A. Defining criteria for disease activity states in juvenile idiopathic arthritis. *Rheumatology (Oxford)* 2016;55:595–596.
- Vervoort T, Trost Z, Sütterlin S, Caes L, Moors A. Emotion regulatory function of parent attention to child pain and associated implications for parental pain control behaviour. *Pain* 2014; 155:1453–1463.



20. Duijster D, de Jong-Lenters M, de Ruiter C, Thijssen J, van Loveren C, Verrips E. Parental and family-related influences on dental caries in children of Dutch, Moroccan and Turkish origin. *Community Dent Oral Epidemiol* 2015;43:152–162.
21. Palermo TM, Zebracki K, Cox S, Newman AJ, Singer NG. Juvenile idiopathic arthritis: Parent-child discrepancy on reports of pain and disability. *J Rheumatol* 2004;31:1840–1846.
22. Lundberg V, Lindh V, Eriksson C, Petersen S, Eurenus E. Health-related quality of life in girls and boys with juvenile idiopathic arthritis: Self- and parental reports in a cross-sectional study. *Pediatr Rheumatol Online J* 2012;10:33.
23. Barbosa TS, Gavião MB. Oral health-related quality of life in children: Part III. Is there agreement between parents in rating their children's oral health-related quality of life? A systematic review. *Int J Dent Hyg* 2008;6:108–113.
24. Gómez-Ramírez O, Gibbon M, Berard R, et al. A recurring rollercoaster ride: A qualitative study of the emotional experiences of parents of children with juvenile idiopathic arthritis. *Pediatr Rheumatol Online J* 2016;14:13.
25. Glaser BG, Strauss AL. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Aldine de Gruyter, 1967.
26. Blumer H. *Symbolic Interactionism: Perspective and Method*. Englewood Cliffs, NJ: Prentice-Hall, 1969.
27. Delle L. *Nordiska hälsovårdshögskolan. Coping with Childhood Disability [thesis]*. Göteborg: Nordic School of Public Health, 2000.
28. Strauss AL, Corbin JM. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, ed 2. Thousand Oaks, CA: SAGE, 1998.
29. Dworkin SF, LeResche L. Research diagnostic criteria for temporomandibular disorders: Review, criteria, examinations and specifications, critique. *J Craniomandib Disord* 1992;6:301–355.
30. 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: 509–535.
31. Connelly M, Bromberg MH, Anthony KK, Gil KM, Franks L, Schanberg LE. Emotion regulation predicts pain and functioning in children with juvenile idiopathic arthritis: An electronic diary study. *J Pediatr Psychol* 2012;37:43–52.
32. Noel M, Alberts N, Langer SL, Levy RL, Walker LS, Palermo TM. The sensitivity to change and responsiveness of the adult responses to children's symptoms in children and adolescents with chronic pain. *J Pediatr Psychol* 2016;41:350–362.
33. Santos D, Silva C, Silva M. Oral health and quality of life of children and adolescents with juvenile idiopathic arthritis according to their caregivers' perceptions. *Spec Care Dentist* 2015;35:272–278.
34. Vanoni F, Suris JC, von Scheven-Géte A, Fonjallaz B, Hofer M. The difference of disease perception by juvenile idiopathic arthritis patients and their parents: Analysis of the JAMAR questionnaire. *Pediatr Rheumatol Online J* 2016;14:2.
35. Stinson JN, Feldman BM, Duffy CM, et al. Jointly managing arthritis: Information needs of children with juvenile idiopathic arthritis (JIA) and their parents. *J Child Health Care* 2012;16: 124–140.
36. Consolaro A, Ruperto N, Pistorio A, et al. Development and initial validation of composite parent- and child-centered disease assessment indices for juvenile idiopathic arthritis. *Arthritis Care Res (Hoboken)* 2011;63:1262–1270.
37. Stinson JN, Connelly M, Jibb LA, et al. Developing a standardized approach to the assessment of pain in children and youth presenting to pediatric rheumatology providers: A Delphi survey and consensus conference process followed by feasibility testing. *Pediatr Rheumatol Online J* 2012;10:7.