

Perceived Oral Health and Care of Children with Juvenile Idiopathic Arthritis: A Qualitative Study

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Aims: To increase knowledge about how children diagnosed with juvenile idiopathic arthritis (JIA) perceive their oral health and dental care. **Methods:** Fifteen interviews with children diagnosed with JIA, aged 6 to 16 years, were analyzed according to classical grounded theory. **Results:** The children's main concern about their oral health was identified as creating a positive identity after being diagnosed with JIA and learning to live with oral health problems. While attempting to cope with this concern, the children often endured in silence, the core category in the analysis. A variety of aspects were found of this core coping strategy, which were categorized as differentiating from the disease, working on personal caretaking and positive attitude, fighting fears and sadness, control of professional aid, and building supportive relationships. The results emphasize the importance for caregivers to show empathy and interest in the child as a person, to ask precise questions when taking case histories so the child does not remain silent, to provide psychosocial support and suggest positive coping strategies, to describe and administer treatments, and to give hope for the future. **Conclusion:** Awareness of the social interaction between a child diagnosed with JIA and health professionals as well as awareness of how to approach a child with longstanding illness are crucial for disclosing and treating the child's orofacial symptoms. *J Oral Facial Pain Headache* 2015;29:223–230. doi: 10.11607/ofph.1293

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Juvenile idiopathic arthritis (JIA) is the most common systemic inflammatory disease in children.¹ It is characterized by persistent arthritis, which can cause growth disturbances and pain. JIA frequently affects the temporomandibular joint (TMJ), and early diagnosis and treatment are crucial to the outcome of the disease.¹

The literature reports TMJ arthritis in children to be unpredictable and often asymptomatic.^{2,3} However, compared to healthy controls, TMJ symptoms and signs are more frequent in patients with JIA but show wide variation.^{4,5} A plausible explanation for this is that a child can have different perspectives on the understanding of pain.^{6–10}

Children diagnosed with JIA have been described as living with general pain that causes them to alternate between hope and despair.^{11–13} Living with pain can have a psychosocial element, and the experience of pain together with the life changes required to cope with it may lead children to feel different from others.^{11–13} A study using the Childhood Health Assessment Questionnaire (CHAQ), a disease-specific instrument developed for JIA that measures disability and discomfort, reported that 34.2% of JIA children ate “with much difficulty,” while 13% performed hygiene, 12% dressing, and 17.7% walking “with much difficulty.”¹⁴ This higher prevalence of eating difficulties compared to other activities shows that orofacial pain and dysfunction have an increased impact on the quality of life for children with JIA.¹⁵

It has been reported that orofacial pain is very common in JIA and is mostly of mild to moderate character.⁴ However, nearly one-fourth of patients experienced severe pain and significant eating difficulties.^{4,15} Such jaw pain might be a sign of increasing disease activity or that the pain is of myofascial origin, leading to adjusted treatment approaches.^{4,16–19}

Because pain when chewing, yawning, laughing, and performing oral hygiene is an everyday experience for children with JIA, they may not be aware that treatments for these symptoms exist.^{20,21} Therefore, clinical examinations and discussions with professional caregivers can be expected as important forums for mutual learning and understanding, primarily through social processes such as interactions between the dentist and the child.^{22,23} Listening to children's descriptions of their care experiences might provide important knowledge to help improve treatment outcomes, but this research area is relatively unexplored. Therefore, the aim of this study was to increase knowledge about how children diagnosed with JIA perceive their oral health and dental care.

Materials and Methods

Grounded Theory

The inductive qualitative method known as grounded theory (GT) was used in collecting and analyzing the data.²⁴ In this study, GT aimed to understand and to examine the children's perceptions of their reality of TMJ arthralgia and dysfunction and their behavior as a result of this problem.^{25,26} A central meaning in classic GT is that identity is developed in interaction with others. This interaction consists of both social actions and cognitive symbols that develop in language.²⁷ GT seeks to discover psychosocial processes and existing problems and to examine how the persons involved handle them, thereby allowing a theory to be identified that is faithful to and illuminates the area under study, rather than to test hypotheses based on existing theory.²⁴ The present study investigated a certain domain of activity, children's daily living with orofacial problems and care. A combination of classic and a modified version of GT, which generates a model for practical/clinical recommendations, was used.²⁸

GT outlines the social processes by revealing the main concern that the subject has; in this study, GT addressed the children's main concern about their orofacial symptoms and the strategies (here named categories) that they use to solve or cope with this concern. A core category pervades the meaning of all other categories.²⁹ GT is especially useful for studying areas where there is little information, for seeking deeper understanding of phenomena, or for exploring new facets of better-known areas.²⁴

Sample and Procedures

Children diagnosed with JIA were purposively selected to form a heterogeneous group, varying in disease presentation, duration, age, sex, and so-

cial and family situation.²⁹ All children were examined according to the Research Diagnostic Criteria for Temporomandibular Disorders (TMD)³⁰ by an orofacial pain specialist within 6 months before the interview.

The subjects had all been referred to the Eastman Dental Institute, Department of Oral Physiology, from the Pediatric Rheumatology Unit at Astrid Lindgren Children's Hospital in Stockholm, Sweden, as part of their care plan. To be included in the study, subjects needed to be 6 to 16 years of age and diagnosed with JIA according to International League of Associations for Rheumatology (ILAR).¹ As such, sample size is less important than in theoretical, quantitative research. The sampling procedure was continued until no new categories were generated in the analysis process; that is, new data gave no new information. The final group comprised 15 children with a female:male ratio of 11:4, which is consistent with the female:male ratio of 3:1 for JIA. Table 1 presents the patients' data. Information about the study was sent to children and parents, asking if the child wished to participate, and written, informed consent was obtained from all parents and children. The Regional Ethics Review Board in Stockholm, Sweden, approved the study.

Qualitative Interviews

The first author (EL) performed tape-recorded interviews in the children's homes; the interview lasted 45 to 90 minutes. The interviewer introduced herself to each child as a dentist with special interest in learning more about children with JIA and started the interview by asking "What do you do all day?" The children were encouraged to speak freely, using their own words. The interviewer asked open-ended questions as casually as possible and followed an interview guide that reminded the interviewer of areas of interest, including questions about the children's perceived relations, facial appearance, jaw function, pain, treatments, oral hygiene, and eating. The interview guide was revised after the first three interviews to accommodate emerging themes.²⁹

Each interview was audio recorded and transcribed verbatim. No software was used to analyze the quotes and data.²⁹

Analysis of Data

The analytical phase consisted of coding the data, a process of defining and categorizing the data. The researchers tried to identify major patterns in the group after coding the interview data.^{26,31}

The research team included a specialist in pediatric dentistry (EL), two specialists in orofacial pain and function (BH-M and ME), a pediatric rheumatologist (BM), and a sociologist with vast experience of qualitative methodology (UH). EL and UH began by

Table 1 Patient Characteristics of 15 Children with Juvenile Idiopathic Arthritis (JIA)

Subject	Sex	Age (y)	Disease duration (y)	JIA subdiagnosis	Medication	TMJ problems perceived by the children
A	Male	14	3	Oligoarthritis	NSAID	No problems recalled
B	Male	6	4	Polyarthritis	Etanercept	Severe dysfunction and orofacial pain
C	Female	15	5	Extended oligoarthritis	Methotrexate	Severe orofacial and neck pain
D	Female	14	2	Oligoarthritis	NSAID	Severe dysfunction and orofacial pain
E	Female	15	8	Psoriatic arthritis	Etanercept	No problems recalled
F	Male	7	3	Oligoarthritis	NSAID	Intensive short attacks of TMJ pain
G	Female	12	1	Polyarthritis	Methotrexate	Pain at jaw movements
H	Male	15	12	Polyarthritis	Etanercept	Problems with looks
I	Female	6	3	Oligoarthritis	None	Pain at jaw function; jaws do not fit
J	Female	14	13	Polyarthritis	Etanercept	Different kind of jaw problems earlier
K	Female	10	4	Polyarthritis	Etanercept	Micrognathia, pain
L	Female	6	2	Oligoarthritis	None	Milder jaw pain
M	Female	16	14	Extended oligoarthritis	Etanercept, methotrexate	Pain and dysfunction
N	Female	15	3	Oligoarthritis	None	No problems recalled
O	Female	9	7	Polyarthritis	Infliximab	TMJ pain earlier

NSAID = nonsteroidal anti-inflammatory drug.

analyzing the data independently using an open coding process and reading the interview line by line, posing the question: "What does the child tell us about his/her perspective"? EL and UH then coded the results, if possible using the child's own words (in vivo coding). After reading the codes and comparing them with each other, EL and UH 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 emerged.

Example: 14-year-old (participant J)

Child: "Maybe this is why it's so good now, because I've had injections."

This quotation was one of many in the analysis that shows a child turning a sad fact into something positive. The codes from this citation were "trusting," "appreciation," "self-care," "posing positive images," "fighting depression," "need of encouragement," "asking for confirmation whether she was right or wrong," and "need of comforting." She had had severe TMJ involvement and endured painful treatments that she was silent about. She was fighting self-pity and depression (which was found in many of the subjects), and trying to view her situation in a positive light. Thus, this quote was coded as supporting the descriptive category *working on personal caretaking and positive thinking*. The quote also supports the categories *enduring in silence* and *control of professional aid*, as she did not mention that she had pain but emphasized in an indirect manner the importance of professional help always being there for her in case she needed it. Finally, it supports the main concerns

of creating a positive identity after being diagnosed with JIA and learning to live with oral health problems.

Throughout the analysis, memos were written to record and track the process.

Results

As mentioned above, the main concern for the children about their oral health was identified to be creating a positive identity after being diagnosed with JIA and learning to live with oral health problems. Data support this as the main concern because it explains the children's behavior in oral health situations. With varying degrees of self-awareness, the children used several strategies to address this main concern. The core category found for coping strategies was enduring in silence, because silence was a prominent finding featured in all the coping strategies (categories) (Fig 1). Despite differences in cognitive development, all the children interviewed fit into this model.

Core Category: Enduring in Silence

All the categories were permeated by silence, because the children avoided talking about their pain; in many ways, the disease made them feel stigmatized and not good enough. They wanted to feel and be like other "normal" children, like the son or daughter that their parents desired; the older patients also wanted to be a person who their friends appreciated. The children thought of their pain as a disease; in other aspects, the children revealed more or less confusion about what was normal about them and what was the disease. They exhibited varying degrees of ability to verbalize this. Still the children expressed

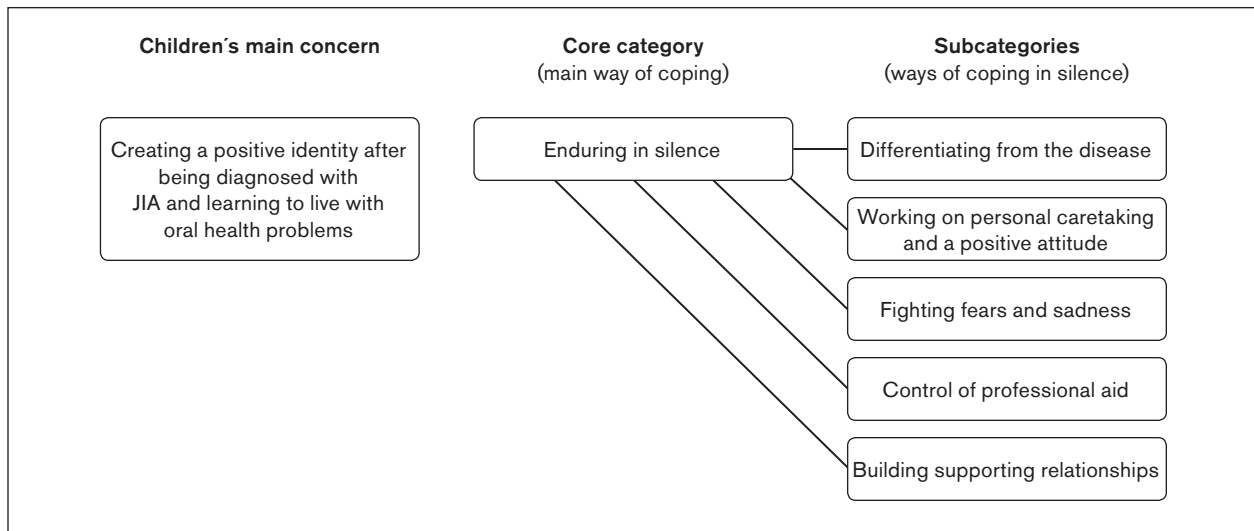


Fig 1 Study results modeling how children diagnosed with juvenile idiopathic arthritis (JIA) think and act with regard to their oral health and encounters with dental professionals.

concern and a need to discuss having a smaller jaw than normal, about their pain, not liking or wanting to take medication/treatments, being bullied by peers, and not being understood by teachers or caregivers. Only when the interviewer showed a positive interest in the child's life, beyond the disease, and asked direct questions, did the children start talking. Boys were generally more reluctant to talk than girls. The children often used the word "boring" and claimed that they did not have their symptoms in mind at the moment. However, the possibility of learning about different therapies interested the children, irrespective of their age, and could also induce them to discuss their problems.

Example: 14-year-old (participant D)

Child: "Yes, they still don't match (the jaws), but you get used to it. It was just that I had such bad problems with my jaw."

Interviewer: "It was painful?"

Child: "Yes."

Interviewer: "But did you tell anybody?"

Child: "Yes, but they noticed when I was unable to eat a piece of tomato."

Subcategory 1: Differentiating from the Disease

The children tried to differentiate themselves from the disease by objectifying, distancing, and normalizing their symptoms. They said this made it easier to cope and took less energy. One way to differentiate themselves from the disease was to objectify and speak in the third person when talking about the disease. They would also distance themselves, for example, by letting the parents take whatever responsibility

was necessary. Children described a shared burden when somebody else understood and took care and responsibility. Many parents palpated the younger children's joints. A young child who refused to mention anything about her pain said: "Daddy knows when you are in pain" (participant I), whereas an older child said: "We contact the doctor when the disease is becoming too much" (participant M). Children stated that they needed to focus on their school life and their friends. Younger children appeared unaware that caretakers could not always understand their symptoms, while older children said that nobody really understood their feelings.

Another way of differentiating themselves from the disease was to normalize the symptoms. The children could spontaneously ask whether this or that jaw function or look was "wrong or normal" for them. For this, the children required the dentist's help with the clinical examination and information in order to normalize with the background of their disease through providing adequate advice and professional help.

Example: 6-year-old (participant B)

Interviewer: "Why haven't you been able to open your mouth wide?"

Child: "I don't know. Because it hurts, I get pain there if I do" (points to the cheek).

Interviewer: "You get pain there, when you open your mouth wide?"

Child: "Yes, and pain when I eat an apple."

Interviewer: "And when you eat ordinary food, is that ok?"

Child: "Sometimes it's ok."

Subcategory 2: Working on Personal Caretaking and Positive Attitude

Older children described how they behaved in relation to their disease when they were younger, doing things such as crying out in pain and expecting their parents to understand their needs. In light of this, the children expressed a need to improve their self-reliance and felt proud when they were able to manage this, “their duty.” The children reported that they were constantly training themselves to think positively. For example, when they were unable to perform certain jaw movements, such as opening the mouth to eat an apple or chewing gum like their friends, this made them sad, but they said that they had to think positively and learn to live with it. The children’s biggest worry was that their behavior was not socially acceptable. They felt embarrassed and exposed, not being able to eat and behave like their peers. Some children also reported that they could not always sing, speak, or laugh for long because of imminent pain and that their faces could go into a spasm and get stuck in a grimace.

Some children mentioned they had learned to swallow food without chewing. They recalled pain on chewing, tiredness in their jaws, or “weak teeth.” They also said they had difficulty chewing, as their jaws did not fit together or were slanting. This was unpleasant and could cause them to bite their cheeks and tongue. Additionally, mouth ulcers made it difficult to speak, eat, and relax. To meet these difficulties, the children adopted coping strategies such as mixing their food in a blender together with milk or avoiding eating in the presence of others.

They addressed difficulties with oral hygiene by only rinsing the mouth instead of brushing or by using electric toothbrushes.

Example: 16-year-old (participant M)

Child: “It seems like she (another JIA patient) isn’t taking care of her disease. I’m proud that I’m able to take care of myself.”

Subcategory 3: Fighting Fears and Sadness

The greatest fears the participants disclosed were of episodes when their disease flares up and of the risk of becoming blind or crippled. Other important fears included being different from others or unable to manage their treatments. They sometimes found living with their pain to be unbearable. The children were not very concerned about the possibility of developing micrognathia, because they felt this would be taken care of. But they found jaw surgery, corticosteroid injections, jaw impressions, occlusal appliances, and orthodontics to be threatening, and they wanted to talk about these fears. Occlusal appliances gave pain relief, but they also reminded the children of the disease. The children specifically associated methotrexate with

sickness, but any pill generated negative feelings that used a lot of energy. Some children reported that they preferred to be in pain than take medication, or that medication did not help the pain.

Example: 6-year-old (participant I)

Child: “If you get an injection . . . I think it’s rather painful. At first I thought it would be painful, but when I got one here, I just said OW!”

“But I didn’t start crying, or did I?” (looks at her mother) “But when I was going to get it, I started crying because I thought it would be painful, but then when I got it, it didn’t hurt.”

Subcategory 4: Control of Professional Aid

When participants were asked about why they were seeing the dentist, they responded that it was because of pain, overbite, crowding of teeth, need for corticosteroid injections, or need to check their occlusal appliance.

While participants said they would appreciate an opportunity to receive orthodontic treatment to improve their facial appearance, they expressed even greater need for an orofacial pain specialist to help if their jaw symptoms flared up. The children often described the jaw as their worst area of pain. They wanted a treatment provider who really understood, recognized, and respected how they felt.

Some children sought to manipulate their professional caregivers, and some were ambivalent toward them. While they viewed their caregivers as a source of support that gave them hope, caregivers also reminded them about having the disease and caused them pain in the course of treatment.

Participants usually perceived intraoral interventions, such as radiography, impression taking, and orthodontic treatments, as painful. In general, the children seemed not to understand that the dental caregiver might be unaware of causing them pain. Some older children explained this as the caregiver not having time to read their file. However, the participants acknowledged that it was necessary for them to endure the interventions.

The children felt vulnerable when meeting a new caregiver who might point out new problems or disabilities. They said that it was important to see how the caregiver responded to them. Most of the children showed very strong positive feelings of appreciation and trust toward their caregivers, but some disclosed feeling hurt or humiliated by them.

Example: 16-year-old (participant M)

Child: “I know when I need cortisone injections in my jaw joints. It’s happened several times now, when the disease has just been crazy painful. Then I call XX and get an appointment that’s convenient.”

Subcategory 5: Building Supporting Relationships

The children said their parents were the best support in their lives. Younger children said that they shared their disease with their parents, even claiming that their parents also experienced their pain. For the younger children it was most important to receive reassurance from their parents of being a “good child,” while older children worried how they were perceived by their peers and that their parents did not let them take responsibility for themselves.

All children expressed a need for support, compassion, and encouragement from parents, teachers, peers, and caregivers, and wanted this support, even if they didn’t ask for it, without having to describe what was wrong with them. From a young age, they felt the need to find and build supporting relationships and it was common for them to say that this was something they always had to work at. The children did not want their peers to know about their disease, if possible. Some related that their peers could forget about the disease, or not understand it, and make humiliating comments. The children often had to plan their activities in detail, and thereby, manipulate their peers in some respect.

Example: 14-year-old (participant J)

Child: “Now they want me to have a splint, but I don’t know. I think that many people maybe wouldn’t want one because maybe they have a boyfriend or something. But me and my boyfriend would probably just laugh at it, because we are so . . . crazy. Yes, I don’t know, I could actually have one, but I . . . it’s just that I don’t feel like.”

Discussion

This study has shown that orofacial pain and dysfunction due to JIA affected eating, sleeping, body image, concentration, oral hygiene, and the ability to speak, laugh, and sing, but children’s self-identity had the highest priority. The results show that children need help not only with their treatment, but also with staying positive after being diagnosed with JIA. The study also exposed beliefs in an omniscient professional caregiver and, for the younger children, an omniscient parent. The findings suggest that dental caregivers need to design holistic, patient-focused treatment strategies when treating children with JIA.

In line with other studies,^{32–34} the results of the present study demonstrate that disease affects a child’s identity to a high degree and that orofacial pain has a high impact on physical functioning and on emotional and behavioral roles, resulting in limitations

in physical activities, schoolwork, and activities with friends. Distancing is a cognitive acceptance approach taught by caregivers as part of learning positive thinking and caretaking.^{35–37} Previous studies have shown that ability to handle the disease can be part of a positive identity.³⁸ The children’s relationship with their caregivers was important, and it helped give the children confidence.³⁹ The subjects in the present study disclosed insecure and unpredictable life situations, difficulties making plans because of pain and dysfunction, not being understood, and a lack of compassion in others for being different.^{40–42} These difficulties have been described in the earlier literature on pain, but not in relation to the orofacial area for children diagnosed with JIA.

The questionnaires can be helpful for screening patients, but they are not useful in the clinical situation for helping the child who must live with pain; in the clinic, supportive dialogue is of vast importance.^{35,36,43}

In the present study, some children were anxious and over-controlling during the interviews, and some, mostly boys, could exhibit somewhat aggressive or ignorant attitudes. It was apparent that even if the younger children knew a lot about their disease and treatments, it was important that they trusted in adults. To build this trust, the caregivers had to form relationships with the children and speak to them candidly, in words they understood, but prevent this information from exposing them to more responsibility and choices than they were prepared to handle. While children were enduring their orofacial problems in silence, the caregiver’s manner was vastly important to the children’s perception of their illness and care.

This study’s strengths included unconditional meetings with the children, which allowed a comprehensive evaluation of various aspects of orofacial symptoms according to contemporary clinical consensus guidelines on pain assessment in pediatric patients.⁴⁴ More research is desired to elucidate children’s symptoms from the orofacial area and the children’s interactions with others, most importantly their parents. The results emphasize how important it is for caregivers to show empathy and interest in the child as a person, to ask precise questions when taking case histories so that the child does not remain silent, to provide psychosocial support and suggest positive coping strategies, to explain and provide treatments, and finally, to give hope for the future. Awareness of the social interaction between a child diagnosed with JIA and health professionals as well as awareness of how to approach a child with longstanding illness and pain are crucial for disclosing and treating their orofacial symptoms.

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