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How children and adolescents with juvenile idiopathic arthritis participate in their healthcare: health professionals' views

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ABSTRACT

Background: The study explores how healthcare professionals view participation of children and adolescents with juvenile idiopathic arthritis, in healthcare encounters.

Methods: This qualitative study includes focus groups of HCPs from different professions. The interviews were analysed with qualitative content analysis.

Results: The theme "Creating an enabling arena" illuminates how HCPs face possibilities and challenges when enabling children to communicate and participate in clinical encounters. HCPs, parents, and the healthcare system need to adjust to the child. The sub-theme "Bringing different perspectives" describes how children and their parents cooperate and complement each other during healthcare encounters. The sub-theme "Building a safe and comfortable setting" includes how HCPs address the child's self-identified needs and make the child feel comfortable during encounters. The sub-theme "Facilitating methods in a limiting organisation" includes how HCPs' working methods and organization may help or hinder child participation during encounters.

Conclusions: HCPs encourage children and adolescents to make their views known during healthcare encounters by creating an enabling arena. Collaboration and building good relationships between the child, the parents and the HCPs, before and during the healthcare encounters, can help the child express their wishes and experiences. Clinical examinations and use of technology, such as photos, films and web-based questionnaires can be a good start for a better child communication in healthcare encounters.

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Adolescent; child; chronic condition; communication; healthcare professionals; participation; qualitative

► IMPLICATIONS FOR REHABILITATION

- Healthcare professionals in JIA teams experience that they can facilitate communication and participation with children and adolescents in healthcare encounters.
- When healthcare professionals enable both children, adolescents and their parents to bring their perspectives, these views complement one another and enrich information during healthcare encounters.
- Children and adolescents are more empowered to participate, when healthcare professionals create a good relationship with the child and their parents, and strengthen the child's knowledge, confidence and autonomy.

Introduction

The United Nations Convention of the Rights on the Child [1] claims that all children capable of forming their own views shall have the right to express those views freely in all matters affecting them, and their opinions should be considered in relation to their age and maturity. However, children often are less active during three-way healthcare encounters (children-parents-healthcare professionals) and decision-making within the healthcare setting [2,3]. Furthermore, children are usually even less active when two parents are involved in healthcare encounters [3,4]. Healthcare interventions for children are often based primarily on parents' reporting [5], although there are well-known

discrepancies between child self-reports and parent reports of child health and health-related quality of life [6–9].

Many children want healthcare professionals (HCPs) to ask them about their health, want to share their own information, and want to be involved in making decisions about their healthcare [10]. Adolescents express more independent behaviours during healthcare encounters [2–4], and girls seem to ask more questions during healthcare encounters [2,4]. However, when adolescents feel they are competent communicators, they may find it difficult to communicate with HCPs [2,11].

This study includes school-aged children and adolescents with juvenile idiopathic arthritis (JIA) as cases for children and adolescents with various chronic diseases. JIA encompasses all forms of

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arthritis of unknown origin with an onset before the age of 16 that persists for more than 6 weeks [12]. Children with JIA struggle with unpredictable phases of incapacitating pain, stigmatization, and physical limitations. Continuous information, strong social and community support, and active involvement in their own health decisions may enhance the children's self-confidence and resourcefulness, conditions that may help them manage pain, improve treatment, and produce better health outcomes [13]. To ensure the best possible outcomes, parents and HCPs need to encourage children to express their concerns and views regarding their symptoms and treatment and consider these when developing and modifying healthcare strategies [14].

Because clinical encounters can trigger feelings of fear and lack of control for many young people, the healthcare system must "get it right" when addressing vulnerable children [14]. HCPs want three-way clinical consultations to promote mutual respect and understanding; an encounter in mutuality [15]. They fear that many children find the experience being an encounter in alienation meaning that the child, parents, and HCPs participate but without actually encountering as a three-part unit. Some part or all of them may not be responsive to each other's expectations and understanding of the purpose with the encounter. Thus, they do not establish a relationship with mutual respect and understanding [15]. Communication with adolescents can also be perceived as challenging and sometimes frustrating [2]. Together with the parents, HCPs have a significant influence on whether the children's efforts to participate are encouraged and supported in healthcare [16]. Therefore, it is of great importance to share HCPs' clinical views, including experiences, opinions and suggestions, with respect to child participation in healthcare encounters with an eye on improving child participation and ultimately healthcare outcomes. Thus, the aim of the study is to explore how healthcare professionals view participation of children with juvenile idiopathic arthritis, in healthcare encounters.

Methods

Study design

This qualitative study is based on focus groups [17] with HCPs in JIA teams. A focus group is a group discussion led by a group leader that focuses on different aspects of a topic or theme. The knowledge that the focus group generates is based on collective shared experiences and emphasises the variation in the collective understanding that emerges from the discussion [17].

The focus groups were analysed using qualitative content analysis (QCA) according to Graneheim and Lundman [18,19]. This method is used to analyse experiences, reflections, and attitudes of people or groups [20,21]. QCA focuses on differences between and similarities within codes and categories. The manifest content – what the core text states – is often presented as categories, whereas the underlying content – what the core texts are about – can be seen as "the red thread" that runs through the text and therefore is presented as themes [19].

Participants and procedure

In conjunction with an annual meeting for JIA teams in May 2017, all 25 participating team members, belonging to in total six JIA teams, were asked to take part in the focus groups. Of these, 20 women and three men agreed to participate. The participants worked at hospitals and treated children and adolescents with JIA less than 18 years old in outpatient settings in four different counties in Sweden. The children's and adolescents' problems and

needs determined which JIA team members had contact with them.

The HCPs, with experience, ranged from less than 1 year to 25 years (median 9 years) of working with children and adolescents with JIA, included five physiotherapists, four occupational therapists, seven physicians, four nurses, two social workers, and one dentist. Written and verbal information about the study were given to all informants along with a written informed consent. The study was approved by the Regional Ethical Review Board in Umeå, Sweden (Approval No. 2017/06-31).

Data collection

Three focus groups were formed, including seven to nine HCPs in each focus group, for practical reasons all disciplines were not represented in each focus group. The focus groups were conducted in parallel in three separate rooms at the Umeå University Hospital. The focus groups were moderated by the researchers (AFW, RJ MS). In focus groups 2 and 3 an observer (VL, CE) accompanied and kept notes, summarized the discussion at the end, and invited the informants to make remarks and amendments. In focus group 1 there were no observer was available thus, the moderator kept notes and summarised the discussion. A semi-structured interview guide was used to support the discussions and the informants were asked to reflect on the following questions: How can HCPs make it easier for children to speak for themselves and participate in healthcare decisions? Did the informants recognize differences between girls and boys and between children's and parents' reports of child health? Could e-health solutions, such as mobile phone applications or telemedicine, improve communication of needs, benefits, barriers, and difficulties? Additional follow-up questions were asked to clarify the statements and reach a deeper understanding of the questions explored. The focus group discussions lasted for 60–65 min and were audio-recorded and transcribed verbatim by a professional transcriber.

Data analysis

The audio-recordings were listened to and the texts were read through in order to correct any inaccuracies. Each focus group transcript was read repeatedly as a whole and in parts during the data analysis. The texts were divided into meaning units, condensed, and read paragraph-by-paragraph. All the details related to the aim were given codes. Codes with similar content were clustered to form categories on a more abstract and interpretative level. The categories were eventually grouped into sub-themes and a theme. The data analysis was started by two authors (VL, AFW) who read, coded, and categorised independently. This analysis was followed by mutual discussions with two authors (MS, RJ) to arrive at a negotiated outcome. In the last step of the analysis, the results were discussed with the remaining two authors (TL, CE). VL, MS, and AFW are physiotherapists, RJ is a usability expert, and TL and CE are physicians. AFW, MS, and RJ have experience with qualitative studies. TL, CE, and VL have a special interest in paediatrics and JIA.

To increase the trustworthiness, the results were presented and discussed with the HCPs at the annual JIA team meeting in 2018, and suggestions regarding the results were included in the analysis. The HCPs concluded that the results were consistent with what they perceived the informants had expressed. The results have also been presented to peers and at an international conference.

Table 1. Categories, subthemes, and the theme presenting the healthcare professionals' views regarding child participation in healthcare.

Categories	Sub-themes	Theme
Child and parent prepare together Children live in the moment Difficulty to tell Parents facilitate Parents have perspective	Bringing different perspectives	Creating an enabling arena
Safe relationships and routines help Positive interaction empowers Safety through knowledge	Building a safe and comfortable setting	
Clinical examinations facilitates communication Technology assists communication Teamwork supports Inflexible organisation inhibit	Facilitating methods in a limiting organisation	

Results

The analysis of how HCPs experienced child and adolescent participation in healthcare encounters resulted in the theme "Creating an enabling arena" with three sub-themes: "Bringing different perspectives," "Building a safe and comfortable setting," and "Facilitating methods in a limiting organisation." The categories, sub-themes, and the main theme are shown in Table 1. The subheadings represent the theme and subthemes and are presented in a chronological trajectory starting before the healthcare encounters. The results include both children's and adolescents' quotations. When presenting the results below 'child/children' include both children and adolescents.

Creating an enabling arena

The theme illuminates how the HCPs face both possibilities and challenges when enabling children with JIA to communicate and participate in clinical encounters. Both younger and older children were perceived as knowledgeable and competent to communicate and participate in matters regarding their health. However, to create a comfortable arena for child participation, HCPs and the healthcare system together with the child's parents need adjust to the child's self-identified needs.

Bringing different perspectives

This sub-theme consists of the five categories: "Child and parent prepare together"; "Children live in the moment"; "Difficulty to tell"; "Parents facilitate"; and "Parents have perspective." These categories covered the HCPs' views on how children and parents cooperated and complemented each other in healthcare situations and how their perspectives could differ.

During the healthcare encounters, the HCPs asked questions, explained treatments, and searched for confirmation from families regarding interventions. To encourage the children to participate in the encounters, the HCPs suggested that children be given information about their healthcare encounter well ahead of time so they could prepare themselves together with their parents for the encounter. This preparation would include the parents and child discussing the child's recent health problems, filling in health surveys together, and deciding what the family wanted from the healthcare encounters. This preparation was seen as especially helpful when the child lived with separated parents in two homes.

The children were seen as both capable of and in need of telling how they felt. The HCPs regarded children as the experts since "they know how it is" and therefore needed to present their opinions as "fellow wanderers" in the communication together with the family and the HCPs. However, children did not always

know that they were allowed or needed to tell about their problems and lives: "[...] [T]hey think that adults understand much more than adults actually do. They think we, as professionals, understand how they feel even if they don't say anything" (Work experience > median 9 years, focus group 1).

At times, HCPs have difficulty encouraging children, especially younger children, to express their health problems. At about 5 years of age children seemed to easily talk with the HCPs, and at about 10 years of age children seemed to express themselves even more as they seemed to better understand how to evaluate their future prospects. Adolescents in their mid-teens, on the other hand, were perceived as "of few words" and "maintaining a mask". They had difficulty opening up and having confidence in the encounter, but were better able to remember past events and this provided the HCPs with more information about their JIA symptoms.

The answers the HCPs received seemed to depend on the HCPs and how they asked questions. General questions about disease and health could give vague answers and result in larger differences between how the parents and the children respond. Specific questions about how problems affected the children in everyday life (e.g., sleeping, eating, being with friends, and participating in sports) was considered to better capture how the children felt.

Younger children were perceived to be living in the moment, the "here and now", not always remembering the past. How they felt during the encounters influenced what they told the HCPs: "If you ask a younger child, how are you? And then they think [...] 'yes I'm fine', although [the child] may not have been sleeping at all during the night" (Work experience > median 9 years, focus group 3). If the HCPs listened and tried to understand the child's life situation by "striving to find the child's world", the children could better tell the HCPs about their health and life situation, which helped the HCPs provide better interventions:

[...] [I]t's a bit about me understanding what they [the children] want to tell. To listen carefully. Based on where they are in life, they can tell quite a bit, but it is important for me to understand from the context it arises from. And it's not always easy. [...] So, based on where the child is in life, I think if we just let them tell what they have to say and listen to the signals, I think they are pretty good at telling about their health. But [...] my challenge is to understand (Work experience > median 9 years, focus group 2).

The HCPs experienced that children perceived themselves healthier and were less concerned than their parents. The children focused on and spoke about their abilities and health in a condensed and positive way. They did not talk about past difficulties but could say "it is good" or "it's mom, she thinks I'm in pain, but I'm not. For me, it works well" (Work experience > median 9 years, focus group 3). This positive attitude was perceived due to the fact that the symptoms, such as pain and stiffness, became

everyday symptoms and therefore the children had become habituated to the symptoms; that is, their reference frames changed during the course of the disease.

Although the children often knew what was wrong, they often became tired of listening to and continually talking about their problems. Therefore, they settled with telling just one HCP and not repeating their concerns to other HCPs. How the children felt on the specific day could also affect how they spoke about their health. For example, if the child was in a bad mood on the day of the consultation, they might not say anything. HCPs also suspected that children could be afraid of revealing how they felt, since it could result in more medications, exercises, blood samples, or more questions. That is, they could respond to questions about their health by saying “it is good” even though they were suffering:

As soon as he said something, it was about problems and then I would come up with further questions or some more injections that I would give him. [...] He spoke much more when he went to the nurse [...] (Work experience > median 9 years, focus group 2).

The HCPs expressed different views with how boys and girls talked about their JIA. Some HCPs did not experience differences in how boys and girls communicated with HCPs, and some HCPs experienced that traditional gender roles were at play: boys tried not to talk about their pain, whereas girls were more willing to talk about their pain.

Parents were seen to have a large role in communicating with the HCPs, especially among younger children who had difficulties explaining themselves and therefore needed their parents to interpret the children’s symptoms and to voice their opinion. HCPs experienced that children could “hand over the disease” to their parents, desiring that their parents handle the communication and answer the questions. Parents made it easier for the children to communicate and participate by remaining silent, letting their children talk for themselves.

The HCPs received information faster if the parents were involved during the encounter, but the children could “think it is embarrassing” when parents spoke about some subjects. Which relation the child and the parent had also affected how the parents perceived the child’s health. Parents often focused on their child’s problems and highlighted these problems when seeking help. But parents could at times overestimate their child’s problems. Parents’ own feelings, such as worries about their child’s future and their own health symptoms were considered to affect how they perceived and looked upon their child’s health:

So it is difficult when you have a patient who says something and the mom says something else. Often, it’s okay. Then usually [...] they realize that, oh, you think that and I say this. What’s correct? (Work experience < median 9 years, focus group 1).

The parents reminded the child of the past, added to the child’s story, and had a broader perspective, providing more details about their child’s feelings and difficulties in everyday life. Therefore, the HCPs wanted both children’s and parents’ views and information, since it often was a long time between the healthcare encounters and much could have happened between encounters.

Building a safe and comfortable setting

This sub-theme consists of the three categories: “Safe relationships and routines help”; “Positive interaction empowers”; and “Safety through knowledge.” These categories cover how the HCPs adapt to the child and tried to make the child feel as safe and comfortable as possible during the encounter.

Communication and participation was facilitated if the child felt supported and safe in the healthcare environment and the routines. Therefore, building the relationship and trust by getting to know the child and creating good contact with both the child and their parents were important. Likewise, the children needed confidence that nothing bad would happen and that they and their parents could rely on the HCPs’ skills. HCPs believed that secure parents make the child feel safer. Therefore the parents were important since they comfort and ensure their child. In addition, it was important that the HCPs addressed the children directly regardless of their age, so the children could participate as much as possible in their own healthcare: [...] if I decide to listen to the child and put the child in first [...] communicate with the child. Or if I turn to the parent directly. There is a very big difference in how I interact to make the child active (Work experience < median 9 years, focus group 3).

The HCPs encouraged children by confirming, praising, and highlighting positive and normal findings. If they gave the child and their families positive experiences and support, the child felt safer and more independent and “then they can be willing to make more of an effort and can tell more about what their problems are” (Work experience > median 9 years, focus group 1). The HCPs interacted with the parents to prepare the adolescents to gradually take more responsibility by giving them appropriate choices, support, and encouragement as well as confirming when they were doing tasks right. In this way, young people learned how to make their own decisions and take responsibility. In addition, the HCPs encouraged the adolescents to be more independent by meeting and interacting with the adolescents without their parents. The information gathered during these meetings were supplemented by the parent’s information, giving the HCPs an even better understanding of the child’s situation. Without the interaction between the HCPs, the parents and the child, the HCPs perceived that the child would not take on responsibility but leave it up to HCPs and/or the parents to take decisions.

The HCPs helped families find appropriate information about JIA orally, visually, and in writing in order to make children feel more secure and safe when taking decisions about treatment options, medication and physical exercise. However, HCPs could not always leave decisions to the child as the HCPs along with the parents needed to take responsibility for these decisions. The information could come in the form of videos that could help the children understand what interventions to choose and what these decisions mean. Children could also need information about what problems are related to JIA. It was not easy for children to understand how one symptom could relate to another: “But for them to be involved in decisions, they need to have good information and better understanding” (Work experience > median 9 years, focus group 2).

Facilitating methods in a limiting organisation

This sub-theme consists of the four categories: “Clinical examinations facilitates communication”; “Technology assists communication”; “Teamwork supports”; and “Inflexible organization inhibit.” These categories relate to how the HCPs perceived their working methods and organization to help or hinder children’s participation in clinical consultations.

Clinical examination methods could facilitate children’s participation. Physical examinations or observations of smaller children in activities displayed the child’s movement patterns, residual symptoms, and what was difficult for the child to perform. Based

on these examinations and observations, the HCPs could ask relevant questions suitable for the child:

I agree that you need to do a clinical examination, that you need to see how the child walks. And similarly if you have a sore knee, you are limping and if you have a sore jaw, it will create a wrong movement pattern and you have to do the examination. And then you can ask some more precise questions and get better answers [...] (Work experience > median 9 years, focus group 1).

E-health solutions were appreciated such as families taking photos, making videos, and sending messages that describe the child's problems to the HCPs (e.g., rashes, swelling, morning stiffness, and how the child participated in activities and schoolwork). Such documentation was considered valuable information and a starting point for discussions, facilitating the communication with and participation of the child. Mobile apps and assessment forms such as the Swedish Paediatric Rheumatology Registry were also considered helpful in communicating with the families and creating a dialog with the child. However, the use of technical solutions was considered time consuming and associated with technical problems, professional confidentiality issues, and problems in documenting in patient records. E-health solutions also demanded flexibility in the teams and the possibility to act promptly on the received requests, which was not always possible in clinical work. However, some families and HCPs resisted the use of e-health solutions.

The teamwork itself was considered effective and facilitating child communication. For each HCP, it was only possible to observe a particular aspect of the child's situation. When a HCP could meet the child at home, in school, or in their leisure time, it was considered an advantage since "it reveals a lot that does not emerge at a hospital visit". The HCP obtained an understanding of the child's function and participation in their everyday life and could share this with the other HCPs. Therefore, the team could "capture what the errand is" and complement each other by helping "put the puzzle" together and obtain a comprehensive understanding of the child's situation. Joint visits, where the child and parents met with all or most of the HCPs at the same time, were perceived as an advantage. The families only needed to tell one history and everyone involved knew what was said and done. Therefore, all those involved could be included in a common discussion and strive towards the same goals where the family members receive the same message.

The HCPs expressed that the healthcare organization was not adapted for optimal participation of children. Children had few and short clinical encounters with the HCPs, which did not favour building a good relationship and information seeking. When the encounters were few and short the HCPs did not have the time and possibility to gather important information about and from the child which limited the team work. Information was perceived best gathered through playing with smaller children or meeting and discussing with older children themselves with and without parents. Furthermore, short visits made it difficult for children to express their problems and concerns.

Discussion

The results show that the HCPs encountered several facilitating factors as well as challenges in their quest for child participation both in the three-way consultations and in dealing with the healthcare organization. The HCPs found it important to listen to the children's and adolescents' opinions during healthcare encounters and perceived that both younger and older children could voice their opinion under the right circumstances.

To facilitate child communication, the HCPs had several suggestions and strategies – e.g., the HCPs should give children and adolescents a chance to prepare themselves for the clinical encounter; the HCPs should adjust their way of communication to the child; and the HCPs should do their best to understand what the child was telling or showing them through activities. On the other hand, the HCPs recognized that the children were adapted to their symptoms and did not know how life could be without their symptoms. Similarly, Todres and Diaz suggest that HCP should engage young people in a "developmentally appropriate way" to ensure meaningful communication and create opportunities for participation [14]. Kodjebacheva et al., review [22] found that children, parents, and HCPs could improve their communicative skills with interventions, implemented strategies, and training aimed at improving communicative skills in three-way consultations. These skills enhance family adherence to treatment recommendations, the health of children, and the effectiveness of the healthcare system [22]. Use of technology to assist communication, such as photos, films or web-questionnaires may also be helpful. Petersson et al. found that children reporting symptoms and health-related quality of life, in a web-based report module, could guide the children to discuss matters with HCPs, which they not had been discussing without results from the assessments [10]. HCPs have the responsibility to ensure children's rights and to encourage and enable children to voice their opinion on issues that affect them during healthcare encounters [23]. The rights of children and adolescents should be reflected in the entire healthcare process, and a child's maturity does not determine whether a child has rights, but rather what weight is given to the child's view [14,24].

The HCPs wanted to know how the children and adolescents participated with peers and in school and "strived to find the child's world". By identifying what motivates and interests the child, participation was also considered to be enhanced. Nilsson et al. also found that children more easily express opinions when questions relate to their everyday lives [25]. Open questions can usually lead to more efficient, accurate patient histories. For younger children, however, closed questioning could work better [26]. According to Söderbäck et al., to capture a child's perspective, parents and HCPs need to be attentive, sensitive, and supportive of each child's expressions, experiences and perceptions [23]. In healthcare, children and adolescents are seen as in need of protection as they are unwell, in an unfamiliar environment, and lack knowledge about medical matters. However, substituting an adult judgement of what is in a child's best interest is not necessarily equivalent with the child's best interest [24]. HCPs are responsible for ensuring children's rights and encouraging and enabling them to make their views known on issues that affect their life [23,24].

The HCPs acknowledged that creating a good relationship and a safe setting were important as this interaction helps set children and adolescents at ease so they feel more empowered to express their concerns about their healthcare and treatment. Other authors have found that adolescents want and need to talk about important health issues, so clinicians who build relationships with adolescents can more effectively encourage young patients to open up [14,27]. However, JIA team encounters that are short and infrequent could be obstacles to building such a relationship with the children and adolescents and their families. In addition, children and adolescents may avoid being active in clinical encounters because they fear bad news, they do not want to cause trouble, they do not want to disappoint HCPs, they do not have sufficient time with HCPs, they are unable to understand medical

language, and they are unable to understand their parents' actions [16]. Coyne discusses that HCPs might not support children's participation for reasons related to their professional role and attitudes and because of a chaotic environment. These reasons also include time constraints, disagreeing with the child's wishes, uncertainty about the child's competence, and lack of communicative skills with respect to children [16].

According to the HCPs, the children and adolescents needed age-appropriate information about their disorder, symptoms, and treatments so they could feel confident and could make informed decisions. In a thematic synthesis of qualitative studies [13], children with JIA also wanted the HCPs to deliver holistic care and ongoing current information about their illness, treatment, and procedures. They also wanted to be informed about medical research and advances in JIA to gain a sense of optimism for the future. The authors suggest that these aspects of support, education, and provision of age-appropriate education for patients and families through the course of the disease be incorporated in the team care plan [13].

The HCPs found parents to be important in child communication in healthcare, especially communicating with younger children because they needed their parent's presence and interference. However, meeting adolescents without parents was a positive experience that could encourage more communication. Other authors have also suggested that the clinician should have time alone with adolescents to provide space for unconstrained discussions even when a parent accompanies them [14,28]. Adolescents have different preferences for physician-patient interaction and their parents' role during healthcare encounters [2]. Some adolescents feel more independent and display a higher degree of self-efficacy in healthcare encounters, while others feel less capable of self-management and want their parents present during consultations. Some adolescents lean on their parents because they feel uninvolved and incompetent or lack confidence because they worry about their health and therefore need their parents to support them in coping with their insecurities [2]. Parents and professionals should view children as individuals with needs that vary according to each situation [24]. Adolescents with JIA reported that they, irrespective of their personality and confidence, liked to talk to doctors and nurses alone [2]. Parents' presence can inhibit adolescents from discussing sensitive topics such as sexuality, heredity, or asking questions themselves, and they can feel embarrassed when parents talk about certain topics [2]. Van Staa et al. found that although adolescents appreciate their parents' active involvement and support, they could find their interference annoying and redundant [2]. Parents can also have focuses and perspectives that do not match the focuses and perspectives of the adolescents when it comes to communicating with HCP [29]. Nevertheless, the parents were seen as supplementary by the HCP, since they could refresh the children's memory. Söderbäck et al. also found that parental or family presence in healthcare settings help establish a truly child-centred approach and should include both the adults' perspective of what they believe is in the child's best interests in terms of care and the child's perspective with respect to the child's own preferences [23]. Adolescents want to have a say in important health-related decisions and are usually not opposed to doctors asking personal questions in front of their parents [2,14].

Children, adolescents and parents had different ways of communicating the child's health to the HCPs. The children were seen to live in the moment, especially younger children, while the parents had a longer perspective. The children often described their health better than the parents described their children's

health, which is in accordance with several survey studies [7–9]. One might speculate whether these differences between child and parent perceptions of child health exist to the same extent in clinical encounters in outpatient settings, inpatient settings, and in child research.

Methodological considerations

A strength of this study is the richness of the focus group data. The informants represented a wide range of experiences in the field of paediatrics, some with long and extensive experience working with children as member of a JIA team and some with less experience. We consider the QCA method as suitable for this study since it focuses on both the subject and the context when analysing experiences, reflections, and attitudes [18]. QCA results are not considered as objective views about the world, but rather the researchers' interpretations of and interaction with the data and the results [18,19].

When conducting QCA, Graneheim and Lundman state that credibility, dependability, and transferability are important measures for achieving trustworthiness [18,19]. For enhancing the credibility in this study, the interview guide was discussed and decided upon among four of the authors, who also analysed the interviews, thus performing triangulation among researchers [30]. Another strength of the study was that the authors represented different professional perspectives including both an "insider" and an "outsider perspective." The authors (VL, CE, TL) have experience working in paediatrics and therefore could be seen as insiders in the field. The authors (MS, RJ, AFW) were more "outsiders" in the field of paediatrics and working with children with the JIA team but have extensive experience with qualitative methods.

The results have also been presented to some of the informants at a seminar group and a conference for member check and peer debriefing [30]. The informants were chosen through purposive sampling, and most of the available HCPs agreed to participate. They had various experiences treating children with JIA and different occupations. However, it would have been desirable to have had more male informants. Krippendorff [31] emphasises that categories should be internally homogeneous and externally heterogeneous. However, human experiences tend to be intertwined, so it is not always possible to create mutually exclusive categories [19], which was true in our study. For example, the categories "bringing different perspectives" and "building a comfortable setting" were somewhat intertwined.

For dependability, all three focus groups had the same interview guide, and in two of them there were observers who summarised the discussions, giving the informants the opportunity to give further perspectives on the content of the discussions in the focus group. In focus group 1 an observer was unavailable. To handle the interview situation, the focus group was led by the researcher with most experience of interviewing and qualitative data collection. She kept notes and summarised the discussion. However, handling all the tasks may have impacted the possibility to pay attention to informants' wishes to make remarks. Open dialogue about the content in the research team further enhanced the dependability. To facilitate transferability, we have been transparent regarding selection of informants, data collection, and analysis while still maintaining the anonymity of the informants. We believe that our results may be transferred to clinical encounters with children and adolescents with other chronic conditions. However, it is the reader's decision whether or not the findings are transferable to another context [19].

Conclusions

HCPs need to encourage and help children and adolescents to make their views known during healthcare encounters by creating an enabling arena. A collaboration between the child and parents before the healthcare encounter, and cooperation between the child, parents, and the HCPs during the encounters will help the child express their wishes and experiences. In the long term, the HCPs can enable the child to participate by creating a good relationship with the child and their caregivers and by strengthening the child's knowledge, confidence and autonomy. HCPs need to interact and communicate with the child in an age-appropriate way, and talk about the child's experiences and challenges in everyday life. Clinical examinations and technology such as photos, films or web-questionnaires can serve as a starting point for child communication in healthcare encounters.

Future research may include exploring practical ways to facilitate child communication at healthcare encounters such as questionnaires directed to children's own perceived health concerns and perceived impact of the symptoms, their interests, dreams and priorities. Questionnaires can form common discussion material for children, their parents and HCP's, and can be presented as an e-health solution.

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