COPING WITH CHRONIC PAIN: IN-DEPTH INTERVIEWS WITH CHILDREN SUFFERING FROM JUVENILE CHRONIC ARTHRITIS.

By Christina Sällfors, Lillemor R-M. Hallberg, & Anders Fasth

Abstract: This study examined from the perspective of children with Juvenile Chronic Arthritis, their experiences of coping with chronic pain in daily life. In-depth interviews were conducted with 22 children (6-17 years). The grounded theory method was applied for analysing the taped and transcribed interviews. Seven descriptive categories were grounded in the data, labelled (1) "controlling strategies", (2) "avoidance strategies", (3) "cognitive strategies", (4) "compliance with the treatment", (5) "seeking social support", and (6) "recovering". A core category was identified and labelled "making me different". The children seem to be caught in a dilemma. In one way the chosen coping strategy reduces chronic pain and in another way the strategy increases stress and feelings of being different from non-disabled peers. Our results indicate the great importance of social support from the children's environment.

Introduction and purpose

Juvenile chronic arthritis (JCA) is a chronic disorder in childhood with pain as an important manifestation (Lowell & Walk, 1989). The disease is unpredictable, but tends to follow a fluctuating course with periods of flare and remission. The average annual incidence of JCA in southwestern Sweden is 11 per 100,000 children and a predominance of girls over boys (2-3:1) is found (Andersson Gare & Fasth, 1992). JCA is a heterogeneous disease, and different subtypes of the disease vary in clinical manifestation, disease course, and age onset (Wood, 1978).

Pain related to rheumatic diseases in children is still a rarely developed area of research and practice, in contrast to the extensive literature on adult chronic pain (e.g. Varni, Blount, Waldron & Smith, 1995; Vandvik & Eckblad, 1990). Chronic pain in children is a complex phenomenon involving a number of components, where cognitive, behavioural and physiological components seem to be the three most frequent components (McGrath &
Melzack and Wall (1996) also focused on the subjective dimension of pain. The child's development, changes in tolerance of pain, memory of pain and differences in responses of pain, are examples on how coping strategies occur (McGrath & Unruh, 1987).

Coping, as a multidimensional process, was defined as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984; Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986 p.141). It is common to differentiate between two main types of coping; problem-focused (e.g. problem solving strategies, seeking social support and confrontative coping) and emotion-focused (e.g. self-control, distancing, escape-avoidance, and seeking emotional support) (Folkman & Lazarus, 1984; Lazarus, 1991).

Coping abilities among children and adolescents differ from those of adults, less stable in children and more changing coping styles during adolescence (Gil, Wilson & Edens, 1997). At about 6 years of age children "are sufficiently aware of stress and coping in their own lives to report conditions and events that they found stressful and describe their own efforts to cope" (Band & Weisz, 1988, p. 251). The ability to use means-ends thinking to solve a problem does not appear until about ages 8 to 10 years and cognitive coping strategies are used as the children grow older (Spivack, 1982; Brown, O'Keefe, Sanders & Baker, 1986).

The effectiveness of coping depends on degree of fit between characteristics of the stressor and the child's preferred style, which could be explained by developmental aspects and environmental conditions (Compas, Malcarne & Fondacaro, 1988). Studies of coping in paediatric populations have favoured the efficacy of more active problem-focused efforts over more passive emotion-focused coping (Compas & Worsham, 1991). In school-aged children social support was the most identified coping strategy after avoidance, emotional, distraction and cognitive coping (Ryan-Wenger, 1994). Rest and distraction were identified as the most frequently used coping strategies among children with arthritis (Abu-Saad & Uiterwijk, 1995).

Research on coping mainly adopts a quantitative approach. This qualitative study focuses on living with pain related to a chronic rheumatic disease (JCA), as described by the children themselves. The main aim of the study was to gain a deeper understanding of how children cope with their chronic pain condition.

Method

Subjects

Twenty-two children (six boys) with JCA participated in the study. The
duration of the disease was 1-16 years (1-16 years for girls and 2-12 years for boys), with data from one subject missing. The inclusion criteria were age between 6 and 17 years and EULAR diagnostic criteria for JCA (Wood, 1978) and no well-known pain from any other disease than JCA. The median age of the study group was 14.5 years (15.5 years for girls and 10.5 years for boys). The EULAR criteria include onset before 16 years of age, disease duration of more than 3 months, and the exclusion of specific alternative diagnoses (Wood, 1978). The following subgroups were distinguished according to EULAR (Wood, 1978): (a) onset with systemic features; (b) onset with polyarthritis in the absence of marked systemic features, five or more joints affected; (c) onset with arthritis affecting four joints or fewer joints - oligoarticular, or in case of only one joint - monoarticular. The study area included five counties with a total of six paediatric departments in southwestern Sweden.

In line with grounded theory methodology, the children were strategically selected due to sex, age, sub-group, duration and activity of disease, geographical location and family situation (e.g. single or both parents, siblings or not). This sampling procedure aimed at forming a heterogeneous study group. Also, categories generated in the analysis process, directed further theoretical sampling that continued until saturation was reached, i.e. new data did not give additional information. Informed consent was obtained from the children and their parents. The research ethics committees of the universities of Gothenburg, Linköping and Örebro approved the study.

In-depth interviews
In-depth interviews were conducted with each child by the same interviewer (C.S.) and lasted between 45 to 60 minutes. All interviews were carried out in the children's home except one, which was carried out at a local hotel conference room. An interview guide with open questions was used beginning with a starting question: “What do you do all day long?” This open question aimed at opening up the interviews, allowing the children to tell about their daily living and how pain affected their life. This open question was followed by questions such as: "What do you do when you are in pain?" "What do you think about when you feel pain?” and “What can you do to reduce pain?” Topics related to these themes were often raised spontaneously by the children or by the interviewer. Each in-depth interview was tape recorded and transcribed verbatim. Qualitative research focuses on different qualities of a phenomenon rather than on its quantity (Baker, Wuerst & Stern, 1992). One important advantage of the present qualitative approach is that the children are allowed to “tell it as it is” in their own words and that their voices can be
heard. The researcher is the instrument, doing reliable analysis of the interview transcripts by systematically coding, comparing and categorising the data (Glaser & Strauss, 1967). The explicit aim of the present qualitative study was to generate new information by opening up a new perspective: the perspective of the children themselves.

Analysis of data
The transcribed interviews were analysed in line with grounded theory (e.g. Glaser & Strauss, 1967). The aim of such a method is to generate concepts, model or preliminary theory. The basic rules of grounded theory include to discover existing problems and to examine how people involved handle them (Stern, 1980). The present study concerned a certain domain of activity, children’s daily living with JCA, which was approached without any predetermined hypotheses in order to explore and explain the emerging phenomena. Starting from the concrete data level, the coding includes a process of reduction and abstraction (Stern, 1980). This coding process could be described in three steps, labelled open, axial (theoretical) and selective coding, starting after the first interview. In sum, the analysis ends up in substantive codes, categories and a core category, where the substantive code is the most concrete level and the core category is the most abstract level. Coding is “representing the operations by which data are broken down, conceptualised, and put together in new ways. It is the central process by which theories are built from the data” (Strauss & Corbin, 1990, p. 57).

In the open coding process the present interview protocols were broken down into segments, conceptualised and given a label, i.e. substantive codes. When suitable, the children’s own language was used in labelling these codes (Glaser, 1978; Strauss, 1987) or a more disciplinary language was used. Each code was compared with other codes, to verify that codes with the same content were given the same labels. The procedure of constantly comparing and contrasting substantive codes with one another aims at finding similarities and differences and to identify situations in which the children act in another way. Substantive codes with similar content were grouped together in more abstract descriptive categories. For example, the category “seeking support” was composed of substantive codes such as “understanding” and “community”.

In the axial (theoretical) coding process, conceptual relationships between different categories were sought. Each category was also further analysed in order to explore its subcategories. The same procedure of constantly comparing and contrasting categories with one another was used in order to secure specificity and precision of the categories. In the selective coding process, a core category (Glaser & Strauss, 1967; Baker et al. 1992) was identified and
labelled "making me different". This core category, to which all other categories were related, was central in the data and guided further collection and analysis of data. The core category showed that psychosocial problems of pain, disease and coping made the children feel different from their non-disabled friends. Finally, a selective review of relevant literature was conducted, in order to identify similarities and differences with the present results. Theoretical notes, i.e. the researchers ideas, reflections and hypotheses based on the data, were made throughout the process in order to keep track of the analysis.

According to Glaser and Strauss (1967), the data should be summarised in as few categories as possible, explaining as much as possible of the area under study, without losing too much of nuances in the data. Also, it is of great importance that the generated categories really fit, i.e. are grounded in the data. A grounded theory study includes quality and trustworthiness in all phases of the research process. Adequacy of evidence, or reliability, occurs when the same phenomena are frequently recurrent. Credibility, or validity, comprises that the phenomena under study could be validated during the constant comparative method (Glaser & Strauss 1967; Baker et al. 1992).

Results

In total, six descriptive categories and one core category were grounded in the data (see table 1 below). The core category, labelled "making me different", described that psychosocial problem of pain, disease and coping made the children feel different from their non-disabled friends. The six categories described qualitatively different ways of coping with pain and were labelled (1) controlling strategies, (2) avoidance strategies, (3) cognitive strategies, (4) compliance with the treatment, (5) seeking social support and (6) recovering. According to Strauss and Corbin (1990), the core category is like the Sun related to its planets.
Table 1. The core category “making me different” and the six descriptive categories and related subcategories.

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<td>Controlling strategies</td>
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Making me different

The relationships between the core category, “making me different”, and the different coping strategies seem to be multidimensional. It was obvious that experience of pain influences the child’s life, giving him/her a perception of being different from non-disabled friends, which was expressed in the following way by one of the children: “I sort of feel like an outsider, really”. Not only the insight about pain and disease makes the child as different from non-disabled peers, but different ways of coping do so as well. “It’s Sports Day at school, and there’s nothing but sports activities. It’s boring not to be in on it, because you miss out on a lot of fun. I was there, watching, for a long time”. This excerpt from the interview shows that coping with pain on one level contributes to the child’s feeling of being like non-disabled peers, e.g. by avoiding sport activities and thereby prevent pain. At the same time this avoiding strategy, and non-participation in the sport activity, makes him/her feeling different from non-disabled peers: “It can be very difficult always having to tell them when I can’t be in on it. Every time you feel like you’re relegated”. This indicates that children with chronic pain seem to be caught in a dilemma. In one way the chosen coping strategy reduces chronic pain and in another way the strategy increases stress and feelings of being different from non-disabled peers. The lives of the children may in some ways look like balancing the
choice between enduring pain and preventing pain by balancing the psychosocial dilemma of participation or not in certain social activities. In sum, the psychosocial problems of pain, disease and coping strategies made the children feel different from their non-disabled friends.

In addition to this dilemma, children with chronic pain conditions like JCA live under considerable unpredictability. One day the child can live like non-disabled children, without being in pain, just to realise that the pain has taken over the next day, making the child different from non-disabled peers again. This alteration of pain was expressed as a strong uncertainty factor in the interviews, which also makes the children different from non-disabled peers. The children’s ideal state is to be like non-disabled friends. It is not important which label is attached to the chronic pain condition, important is rather the extent to which pain and treatments disrupt the child’s ability to maintain everyday activities. The following excerpt might exemplify the unpredictability: “Now my little sisters got it too, so it’s a bit of a shame. She’s also kind of thin and bony. It’s a shame really, because she also wants to be jumping about. My other sister who doesn’t have rheumatism isn’t thin and bony. She’s like everybody else”.

The category shows that the children take a high degree of responsibility for their own health by making priorities and decisions about their activities: “I have to think one step ahead”. This implies a trust in your own ability to treat yourself. The child takes the disease into his/her own hands: “If there’s a problem I’ll tell them. I’ve learnt a great deal about my illness, because I want to know what it is. It’s part of my life”. The result shows that the children grow physically and mentally and are in ways largely different from the non-disabled peers. Taking command and doing one’s best
of the situation are strategies described by the children. Instead of giving up, the child sometimes participated in painful activities in order to be like the non-disabled children of the same age: “Specially when it’s a disco or something, then I’ll take a pill and I’ll go there, and then I have to rest for a day. You just have to be in on it. You can’t skip everything”.

Avoidance strategies

This descriptive category includes three subcategories: ignoring, excluding and withdrawing. Avoidance is a natural method for preventing progress of the pain, but can in daily life be experienced as a feeling of being different. The restrictions are a direct consequence of the chronic pain condition. The children avoid activities they perceive as potentially pain-triggering because of their anxiety about pain: “I’m afraid of being pushed, so I try to avoid being too close to them when they’re fighting at school”. Writing is for many children very difficult and hurts very much, so instead they use a computer. This type of avoidance is constructive for many children. Some of the children were given cards for the photocopier, so they could make as many copies as they liked instead of writing it all themselves. The importance of education cannot be overestimated. All degrees of extra practical help and arrangements at school could, however, result in feelings of being different. To minimise these feelings of being different from non-disabled peers, the children sometimes ignored their pain and how they “should” cope with it. Ignoring as a strategy could be illustrated by the following quotes: “I don’t care that it hurts” and “Even though it hurts, I don’t care. I’ll walk anyway. I won’t sit still”.

Excluding activities is a common way to manage pain. In periods of pain, the children choose to exclude physical activities and adapt their lives to the condition of pain: “It can be very difficult always having to tell them when I can’t be on it. Every time, you feel like you’re an outsider”. When in pain, it was difficult to be spontaneous and impulsive which generated feelings of hopelessness for the child. For some children this hopelessness led to some form of giving up. Withdrawing from potentially painful situations, such as social gatherings and football games, is also a common way of coping among children to avoid painful experiences. The restrictions can also operate indirectly. Boys may be discouraged from joining the football matches, just in case an accident happened. Some children prefer to stay at home when their friends go to parties, the cinema and to meet other friends: “When it hurts really badly, I can’t cope, then I stay at home”. The children felt sad and different from other none-disabled peers when they need avoiding strategies managing pain conditions: “You get sad and cross and you take it really bad. It really gets you”.
Cognitive strategies
This category is composed of three subcategories: positive thinking, talking to oneself and wishful thinking. Thinking positively was a way of cognitively coping with pain. The children convinced themselves that they never had to give up. The experience of chronic pain sets the children apart from their non-disabled peers. In knowing that they have coped and come through cruel stages of pain conditions, the children may have gained some insight and autonomy in comparison with their non-disabled peers. The chronic disease can act as a stimulus to the promotion of psychological growth, which made them different from non-disabled peers. The children turned bad experiences into good ones, i.e. cognitive reappraisal: “You should think like this, there are people who are worse off. It’s not too bad, actually. Think a bit positively, otherwise it’ll only get worse”. Another child could think positively, because of the trust in Goodness: “It’s like, the scientists are very good and all that. I’m sure things will get better”. The children, as a way to persuade themselves that sports aren’t important, described talking to themselves, for example in sports: “I don’t think a person should have to do sports”. The same strategy was described in relation to bloodtests and treatment at the hospital as well as medicine intake. Even in the deepest despair the children’s wishful thinking could be seen: “I’m going to hospital soon to have a new hip joint and then I hope I’ll be better”. Another child had a different wishful thought: “I actually think I’m better now, because my inflammation doesn’t come so often. I’m not in pain all the time”. The following quotation illustrates cognitive strategies: “The perfect day would be to get rid of your illness just for a day. I’d do anything for that. That would be living. It would be great to know what it’s like not to be in pain. I’m in pain every day.”

Compliance with treatment
This descriptive category includes three subcategories: medicines, physiotherapy and technical aids. Medicines are essential in managing pain. The majority of the children expressed their positive attitudes towards medical treatments. The drugs often have only a short duration and may even have harmful side effects. The children, except the youngest one, described their dependency on different treatments and techniques. This dependency of treatment also points at the dilemma the children have to deal with. Although the treatment might reduce pain, the child feels different from non-disabled peers, who are independent of treatments, drugs and professional consultations. However, the children expressed great confidence in the drugs because the drugs were often helpful: “I think my drugs are really good. They’ve given me this special medication and it’s so good that I reckon if I’d had it from the beginning, I would have been really well now”. On the other hand the
children know very well that the drugs often only have a short effect on the pain: "I'm anaethisised for a couple of hours anyway. Yes, it feels better then". One child used homeopathic medicine, and the child had got a simple explanation of the disease from the homeopath: "We went to a homeopath. He said I drink too much milk. He warned me against milk, white bread and pork. We’ve started now". Most of the children had periodic physiotherapy and experienced it as reducing the pain: "I tell them where it hurts at the moment, and the physio tells me what to do. You build up your muscles, so you've got something to hold it in place, so it won't hurt as much". Popular treatments include heat: "A wax bath doesn't improve things, but it's nice while it lasts". The children perceived that physiotherapy in water was essential for them: "Lying in a lovely warm hot tub, there's nothing better in life". The children used different kinds of technical aids all day long, both in school and at home: "I feel comfortable in my wheelchair. I feel like a king". Other children used the aids on special occasions: "I use the hand orthoses when I play basketball and stuff at school. They're really great".

Seeking social support
This descriptive category consists of three subcategories: practical help, emotional support and professional support. Our findings indicate the great importance of social support from the children’s surroundings. This seemed to be an accentuated need, which increased the feelings of being different from non-disabled peers. The children do see themselves as highly dependent on practical help, emotional and professional support. The challenge in adolescence is to achieve the desired independence and autonomy, while at the same time, maintaining close and supportive ties with the family. The children needed practical support in everyday life, both at school and at home: "I’m in a wheelchair sometimes because I’m in so much pain, then he’ll push the wheelchair for me and stuff like that". The children consider family and friends as the most important resources in life. The children felt respected by their family and by friends. The family seemed to be the most essential factor and secure foundation that included love, confidence and empathy for the children: "The thing for parents is to make you believe in yourself". However, the children also need friends not only for pleasure but also for essential training in social competence: "I've got a friend and she’s got it too. We ring each other and say that now it’s painful again". Many children were members of a support group for young rheumatics, which gave them positive emotional support. They were not alone with their pain and they could share experiences of being in the same situation: "When we got to the camp there were lots of people who were much worse than me who came in wheelchairs. They told us
how they felt about things and you sort of gained an insight into it all. That it’s not just me, because sometimes it feels like, here I am, and everybody else is there, like somewhere I can’t be, and that’s awful”.

It seems important to the children to get support from professionals at school and from health care authorities. If the children were met with understanding and respect they could better manage treatments at the hospital. The children in the present study experienced that they had got adequate information and that their co-operation with health care staff was characterised by confidence: “I always ask, and it’s usually not very difficult to understand”. School professionals include all the professionals in school, e.g. teachers, school nurses, and assistants. The interviews indicated the important role of the school nurse: “Our school nurse is really great. She’s someone who really cares. She also remembers everybody who’s been to see her”. All pupils are in a special situation in school because you have to be there, whether you can or cannot. Children of school age, as opposed to working adults, have no choice but to attend school they are obliged to by law. A working adult may be sick-listed whereas a child cannot miss his or her education. This dependence of practical support made the children different from non-disabled peers. “It a bit difficult you know, to say this every time we get to a door: Would you mind opening it for me?”

Recovering
This descriptive category is composed of three subcategories: rest, heat and relaxing leisure activities. Children with chronic pain often feel tired and they need to rest several times during the day: “I’ve become much more reserved. I go to my room and sit down to watch TV or something. I need so much more rest”. This need, and dependency, on warmth and rest is an additional circumstance differentiating these children from non-disabled peers. The children in the study described that they often went to the school nurse to have a quiet place to rest. When in pain, the child often preferred warm socks or a warm blanket to his or her legs. Rest and heat seem to be very common key strategies in coping with pain: “Resting is great. It feels like it helps more than anything else does”. The children distract their attention from pain by listening to music, reading or doing other leisure activities. The children perceived that they got energy from selected leisure activities, such as visiting the stables even without riding: “The best comfort there is, is from horses. That’s how I solve my problems anyway”. In their leisure time the children can find relaxation and feel better. They can feel joy of freedom without feelings of pain, which can be seen as a distraction strategy: “When I’m on horseback, I feel great. It’s lots of fun and I don’t feel any pain”.

SJDR – Volume 3, No.1 – 2001
Discussion

This qualitative study aimed at describing experiences of coping with chronic pain in 22 children with JCA. It was obvious that children with JCA lived under considerable life stress due to the unpredictable progress of functional disability and chronic pain. Also, the children were confronted with many stressors caused by their chronic pain. The main finding was that the children’s pain as well as their coping strategies, made them feeling different from non-disabled children. Feelings of being different were combined with feelings of being lonely and sometimes even alienation from other peers. Their feelings of being different from non-disabled peers could also be expressed in terms of deviating from normality, which indicates that children with chronic pain seem to be caught in a dilemma. In one way coping reduced their pain and in another way the coping strategy increased stress and feelings of being different from non-disabled peers. Daily life of children with JCA could be described as balancing the choice between enduring pain and preventing pain by balancing the psychosocial dilemma of participation or not in certain social activities. Our study has thereby contributed with new knowledge showing the dilemma of coping with chronic pain in childhood, generated from interviews with the children themselves.

Chronic pain related to JCA seems to result in the same sorts of strained social interactions that are described as typically striking for individuals with other stigmatising conditions (Goffman, 1963). According to our study, the children’s coping with chronic pain was not always a linear process. Rather, the children described “ups” and “downs” and they emotionally balanced between feelings of hope and despair. Investigators (e.g. Woodgate, 1998) have stressed adolescents’ perspective of chronic illness described their feelings of being different from others due to the illness but, contrary to our findings in children, not because of their coping strategies, whereas others (Lindström & Köhler, 1991; Varni, 1992) have stressed negative attitudes towards physical differences from others.

Most of the children in our study were adolescents, and this period of life is generally stressful to all young people. Adolescents experience psychological (e.g. cognitive abilities) physical (e.g. pubertal growth) and sociological (e.g. school changes) demands. Some challenges in adolescence are to achieve independency and autonomy, while at the same time maintain close and supportive ties with the nuclear family. In addition to these challenges, adolescents with chronic pain have to cope with daily stressors related to their pain and disease.
Theories of coping highlight, besides the function of coping as managing or reducing threat in stressful situations, the regulation of distress (Lazarus & Folkman, 1984; Lazarus, 1991). For the children with JCA in the present study, the distress was not reduced by their coping with pain, rather the children described feelings of being different from others as a consequence of their coping efforts. Except their coping behaviours, both actual physical and social barriers contributed to their experiences of being different. The children reported deficiencies in two distinct areas, social and physical activities, mostly as a result of pain, but also as a result of disease and disability.

All children in the study used a variety of coping strategies. Avoidance strategies, described in the present data, as well as in earlier coping research (Tesler et al. 1981; Gil, Thompson, Keith, Tota - Faucette, Noll & Kinney, 1993) have similarities to emotion-focused coping and escape coping. Escape coping is similar to withdrawing (Tørestad, 1990), which the children in the study described as a way of coping with pain. The children frequently used controlling strategies, including planning the daily activities. Controlling strategies have similarities to active and problem-focused coping. The children know very well, even the youngest one, what they need to plan, but they didn’t always like it. Their perception is that they can’t be as free as their non-disabled friends can.

Abu-Saad and Uiterwijk (1995) reported rest as a frequently used coping strategy which was also reported by the children in the present study. During periods of rest the child in our study mobilised energy for further activities but at the same time this behaviour made the child different from non-disabled peers. This means that the child frequently was caught in the dilemma. Earlier research has found that girls report more coping strategies and vary their strategies more than boys (Tesler et al. 1981) do. On the other hand, it has been reported that boys more often use distraction as a strategy than girls, who instead use heat strategies more frequently (Tesler et al. 1981; Savedra, Tesler & Wegner, 1988). According to Folkman et al. (1986), it is important to recall that coping efforts in childhood change not only as a function of situational factors related to the stressor, but also as a function of the developmental level of the child.

Social support seemed to have a buffering effect in coping with pain and illness. In the present study, social support seemed to protect the children from stressful life events. Despite the positive effects of social support on stressful events and pain, the dependency on others made the children feel different from non-disabled peers. In accordance with Ryan-Wenger (1994), family support was the strongest coping strategy in both the younger and older children. The family as a resource for the child’s
development and socialisation has been a challenging subject for researchers in behavioural and social science for many years. According to Bowlby (1994), the family represents a "secure base". Hansson (1990) defines social support in three dimensions: emotional, informative and material support. Based on our data, the category "seeking support" includes a continuation of all three dimensions of social support as well. Based on our data the category "social support" includes a continuation of all three dimensions of social support. Our data also highlight the importance of social support from professionals at school and at clinics. Befring (1993) describes the high price the children have to pay at school in relation to both teachers and fellow pupils. Social interactions are crucial for maintaining the self-image and the social roles. There are invisible rules for what is and is not accepted in all types of social interactions. Special rules apply in the breaks at school and others in the classroom, and still other rules work at home. Our results show that children with chronic pain have considerable difficulties in social interactions at school, because they feel different from the non-disabled children.

The results show that pain is a substantial problem for children with JCA. It is essential that family and health care professionals dare to acknowledge the child's existing pain and his/her suffering and coping with chronic pain. Leikin, Firestone and McGrath (1988) found that young children underreported their clinical symptoms. Although very few children between 6–10 years participated, our data indicated that the younger children described pain coping differently than the older ones. Older children described avoidance strategies and cognitive coping more often than younger children. Although the aim of this study was not to explore age and gender differences, some age-related differences in coping were indicated in the data. The older children, but not the younger ones, often decided consciously to avoid physical activities in coping with their pain and thereby they found a balance in daily life. However, the prize they had to pay was feeling different from the non-disabled peers. The older children in the study expressed that they had gained insight into the meaning of their disease and also reached personal autonomy in comparison with both the younger children and non-disabled peers. The children in the study, both the older and the younger ones, often tried to turn bad experiences into good ones, in order to handle their life situation. This cognitive strategy could be seen as a way to endure one's situation. The older children expressed more worry about missing school - work and social functions and activities with peers than did younger ones. The younger ones often expressed great confidence in drugs and treatment and were, of course, more dependent on their parent's opinion of their situation. The
youngest children were more dependent on all kinds of practical support in everyday life than the older ones, who had more resources such as other adults and friends. The girls in our study used a broader repertory of coping strategies than the boys, which was also reported by Spirito, Stark and Tyc (1989). However, the overall finding is that the children, according to age and gender, did express more similarities than differences in coping with chronic pain.

JCA differs from other chronic diseases in childhood, as it is invisible during some periods. The duration of JCA in our sample varied from 1 to 16 years. This means that some children identified long periods during their early lives as painful and restricted by treatment, coping strategies and serious suffering. The children had developed a wide variety of coping strategies. This is consistent with the notion that children with chronic diseases need to adjust to external and internal demands which they are going to meet in the course of disease and treatment (Holroyd & Lazarus 1982). Schanberg and colleagues (1997) stress “extent of disease activity” as an important predictor of pain. Although the extent of disease activity was stable in most children in the present study, they described painful and restricted lives and use of different coping strategies, contributing to making them different (in a negative way) from none-disabled children.

The EULAR criteria (Wood, 1978) for JCA were used for inclusion in the study and children with known pain from other diseases were excluded. The polyarticular subgroup dominated in this study. Andersson Gäre and Fasth (1992) presented the distribution of subgroups of JCA, where the oligoarticular subgroup dominated before the polyarticular subgroup (Andersson Gäre & Fasth, 1992). Six of the children in the present study were 10 years old or younger, but despite their young age they were all good informants. Using children as informants of own experiences has been documented as valid and reliable (Amato & Ochitree, 1987; Deatrix & Faux, 1991; Sorensen, 1992; 1993). Also, Deatrix, Faux and Moore (1993) found that children can describe their illness experiences adequately. Although girls dominate in JCA (Andersson Gäre & Fasth, 1992), this is not a sufficient explanation of the small number of boys willing to participate in this study. The small sample of boys might be explained by their underestimating of pain in order to be seen as “brave boys”, which was suggested by McGrath (1990), Klonoff (1993) and Fearon (1996). Another possible explanation might be that, since boys’ activities tend to be more physically demanding than those chosen by girls, boys with JCA also pay the highest price in terms of being different from their non-disabled friends, as their pain may prevent them from participating in physical activities.
JCA is a chronic disease in childhood that has multiple phases, each of which needs different types of research and care. The insider perspective of this qualitative study generates new knowledge about pain coping strategies in children suffering from JCA. One major goal for our future research will be to look further at the ambivalence of coping strategies in relation to being made different. Another goal is to determine whether certain coping strategies are inherently adaptive and others less effective. Also, our future research will focus on gender differences in coping strategies in paediatric populations.

Acknowledgements: We thank all the children for their participation in the interview study. The present study was supported by grants to Christina Sällfors from the Swedish Rheumatism Association; The Norrbacka – Eugenia Foundation, Renée Enander Foundation, The Committee for Mental and Physical Disabilities, The Health and Medical Care Executive Board.

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