Consulting the ‘experts’: children’s and parents’ perceptions of psycho-educational interventions in the context of juvenile chronic arthritis

J. H. Barlow, K. L. Shaw and K. Harrison

Abstract

There is little documented information regarding current provision of psycho-educational interventions in the context of juvenile chronic arthritis (JCA). The purpose of the present exploratory study was to gain insight and understanding of the needs and preferences of children with JCA and their parents, and to examine how these may be more adequately addressed by future psycho-educational interventions. Data were collected through focus group discussions with children, parents and health professionals, respectively. Results showed that the voices of children and their parents were as one in calling for greater availability, easier access and more comprehensive psycho-educational interventions in the context of JCA. Greater emphasis is needed upon the social and emotional aspects of chronic disease, and enhancing the self-management skills of children and their families. Moreover, content should be tailored to match broad categories of disease severity (e.g. mild or severe), developmental age and stage in the life course (e.g. child or adolescent). Group education, informal support groups, activity weekends and summer camps would be particularly welcomed by parents and children, and may serve to reduce their sense of isolation whilst providing much needed reassurance. Findings provide a useful set of signposts to guide future development of psycho-educational interventions in the field of psychosocial paediatric rheumatology.

Introduction

The widespread belief that arthritis is a condition of ‘old age’ is a myth. Juvenile chronic arthritis (JCA) is one of the most common chronic diseases of childhood with an estimated world-wide prevalence of between 0.16 and 1.13 per 1000 children (Benjamin, 1990). In the UK, the annual incidence of JCA is approximately 1 in 10 000 and recent figures suggest that over 15 000 children are currently known to have the disease (Arthritis and Rheumatism Council for Research, figures for 1994). Classified as a heterogeneous group of disorders, JCA is characterized by persistent inflammation of the joints that presents before 16 years of age (Munthe, 1990). The disease follows an unpredictable course, and thus for many children life with JCA fluctuates between periods of active disease and remission. Typical symptoms include pain, stiffness, swollen joints, fatigue, lack of appetite and general irritability. Prognosis is uncertain, and in the absence of curative treatment, primary therapeutic goals are to reduce pain and inflammation, maintain joint function, promote muscle strength, prevent disability, and control extra-articular manifestations such as iritis. Disease management is complex involving a combination of diverse therapies (e.g. medication, wearing splints and exercise), and regular visits to various out-patient clinics such as rheumatology, ophthalmology and physiotherapy. In addition, JCA requires constant monitoring and performance of self-care activities.


The responsibility for day-to-day disease management quickly shifts from health professional to parents and children, although adolescents are expected to play a greater role in accordance with their growing independence and autonomy.

The impact of JCA and its management upon the family is considerable. Up to one-third of the child’s free time may be lost due to arthritis (Southwood and Malleson, 1993), and the family’s involvement in health regimens can severely restrict personal time, holidays and leisure pursuits. Concordance is believed to be less than optimal (Rapoff and Christopherson, 1982) and forms a major area of concern (Kroll et al., 1998). Not only may poor concordance reduce the potential benefits of treatment for individual children and their families, but on a wider scale may serve to increase health costs (Rapoff and Christophersen, 1982; Varni et al., 1984).

Many families appear to adjust well to the presence of JCA, whilst others are less successful (Wallander and Varni, 1989; Miller, 1993; Revenson, 1993). Poor adjustment in the child has been related to a variety of factors including parental dysfunction, high family stressors, scarce family resources and low family cohesion or harmony (Harris et al., 1991; Vandvik and Eckblad, 1991; Timko et al., 1992; Ross et al., 1993). Reciprocally, the child’s psychosocial functioning can influence other family members. Indeed, adaptation of both child and parents are as closely linked to the child’s psychosocial well-being as they are to disease status (Timko et al., 1992).

**Psycho-educational interventions in JCA**

Psycho-educational interventions have a major role to play in the context of chronic disease and JCA is no exception. Not only do children and their parents require sufficient knowledge and understanding to make decisions regarding treatment options and lifestyle changes, but also they need the necessary skills and confidence to manage JCA in the home environment (Barlow, 1997). For the purpose of this study, psycho-educational interventions are operationalized in accordance with the definition of health education proposed by Tones (Tones, 1997), as intentional activities designed to achieve disease-related learning, and that may lead to changes in knowledge, understanding, beliefs, skill acquisition or behaviour. Thus, psycho-educational interventions may encompass information-based materials, cognitive-behavioural programmes and self-management programmes (see Table I). Interventions can be delivered to an individual or a group and in clinical settings or community settings (e.g. home, school).

The need for improved educational intervention within the field of paediatric health care has been highlighted in a number of reports (Beresford, 1995; Diehl et al., 1991). In the context of JCA, most hospitals and relevant voluntary organizations appear to offer some form of educational intervention although the level and effectiveness of provision is difficult to determine. For example, a recent review of psycho-educational interventions for children with JCA (Barlow et al., 1998) identified only nine published studies, most of which were conducted in the US and concerned specific interventions (e.g. increasing medication ‘compliance’) among selected groups of children. None of these interventions were suitable for widespread distribution in a range of settings, such as outpatient clinics, general practitioner surgeries, schools or the home environment. This apparent short-coming has been recognized, and increased attention is being paid to the development of interventions for children with JCA and their parents.

**The study**

As research health psychologists we are invited to participate in evaluations of interventions for children with JCA and/or their parents (e.g. workshops, computer multi-media programmes). Although most of these interventions involve children and/or their parents at some stage, our experience suggests that this occurs after the intervention has been designed and when there is little opportunity for more than minor adjustments to be made to content or format of the intervention. Anecdotal information received from children and parents suggested that current interventions may be failing to address key issues perceived as important by
the very people they were designed for. Thus, the present study was undertaken to provide insight and understanding of the needs and preferences of children and their parents, and to examine how future psycho-educational interventions may more adequately address these needs and preferences in terms of availability, content and format. As such, the study had an applied focus, and was designed to provide the foundation for developing and evaluating psycho-educational interventions in paediatric rheumatology. An in-depth theoretical analysis setting study findings in a conceptual framework is beyond the scope of this paper. Rather, we will focus on presentation of children’s, parents’ and health professionals’ perspectives on key issues relevant to the development of future psycho-educational interventions. We felt that this approach was appropriate, given the failure of previous interventions to listen to the voices of the experts: children and their parents.

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**Method**

To ensure the aims of the study were met, an appropriate methodology was selected that enabled the voices of children and parents to be clearly heard, not only in the expression of their current needs but also in the articulation of their views regarding interventions of the future. Focused group discussions were selected as a suitable method that would enable participants to raise issues that they felt were important, rather than issues determined by ourselves as research health psychologists.

**Focused group methodology**

The focus group is described as a group interview that seeks to capitalize on communications between participants in order to generate data (Kitzinger, 1995). Since attitudes and opinions are both formed and articulated within a social context, the focus group provides an interactive dynamic for developing, challenging and refining ideas. By actively engendering a permissive atmosphere within the group, focus group methodology aims to generate a situation whereby a more complete and thorough understanding of key issues is obtained (Vaughan et al., 1996).

Focus groups typically consist of six to eight people who meet to discuss an area of common interest in the presence of a moderator. The challenge for the moderator is to facilitate the flow of discussion whilst concomitantly holding the discussants on task. Discussions typically last between 60 and 120 min (although a shorter duration is usual when involving children), and during the course of discussion the moderator will seek to ascertain the range of opinion held by the group. Compared to the normally passive role assumed by research participants, the focus group offers a more empowering experience for all involved (Harrison and Barlow, 1996).

**Participants**

Five focused group discussions were held with each of the following groups; health professionals ($N = 7$), children designated as having ‘mild’ JCA ($N = 5$), children designated as having ‘severe’ JCA ($N = 5$), parents of the ‘mild’ children ($N = 6$) and parents of the ‘severe’ children ($N = 7$). The health professional group included a paediatric rheumatologist, and representatives from nursing, physiotherapy, occupational therapy and disease educators. The parents’ group comprised four fathers and nine mothers, and the children’s group...
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included five boys and five girls aged 8–15 years. Due to ill health, two children (one boy and one girl) were unable to attend the focus groups and were individually interviewed at a later date. Whilst no new themes were identified from these individual interviews, the inclusion of both sets of interview data was felt to provide greater insight into children’s perceptions of health education. All participants were recruited through the Children’s Arthritis and Rheumatic Diseases Unit (CARDU), Birmingham.

Procedure

Four focus groups (parents and children) were conducted at the Birmingham Children’s Hospital and one (health professionals) was held at the Department of Rheumatology, Birmingham University. On each occasion, participants assembled in a quiet room where the procedure of the focus group was explained. A set of questions was developed and used as a means of generating discussion around the topics of interest: perceived needs, views on the availability, content and format of existing interventions, and views on future interventions in JCA.

The discussion was facilitated in a non-directive manner by an independent moderator and written notes were taken by an assistant moderator. Each focus group was tape-recorded with the permission of participants. The focus groups with adults lasted approximately 120 min, the focus groups for children were shorter (i.e. 90 min). At the end of each discussion, a summary of results was read back to the group enabling participants to verify, amend and prioritize emergent issues.

Analysis

The audiotapes were transcribed in full. Analysis of each transcript was made with reference to the written notes in order to minimize potential decontextualizing of data. The process of analysis followed the steps recommended by Krueger (Krueger, 1994). In summary, data was reviewed for emerging themes, coding categories were subsequently developed, the data sorted in reference to them and topologies constructed. Analysis was conducted independently by two researchers. High inter-rater agreement (96%) was achieved in the identification of themes and categories. Issues raised within the focus groups are exemplified in the quotes used in the following section. All participants’ names have been changed to conserve anonymity.

The results are presented under the following broad topic areas, which are not mutually exclusive:

- Perceived needs.
- The experience of psycho-educational interventions: access, availability and content.
- Thirst for knowledge.
- Future psycho-educational interventions.

Results

Perceived needs

The expressed needs of children with JCA and their parents were predominantly psychosocial in nature. Children felt that every aspect of JCA and their health-care served to make them look, feel and behave differently from their peers. Consequently, their greatest concerns were for peer belonging and social acceptance. Adolescence emerged as a particularly difficult time: children who developed JCA or experienced a return of active symptoms during this time reported that they had more adjustment difficulties than those who had been diagnosed as toddlers and had ‘grown up with it’. This point was confirmed by parents.

The foci of parents’ concerns were to ensure that their children had similar opportunities for self-development as children without JCA and to provide a sense of ‘normality’ in children’s lives. Parents expressed immense frustration and anger at the number of social barriers that thwarted attempts to achieve these goals. They felt that their children met with discrimination and criticized both Health and Educational services for a perceived lack of support and assistance. Children at the milder end of the disease spectrum appeared particularly vulnerable in this respect. When JCA was less visible, children and their families reported a lack of both institutional and personal support.
In order to meet their children’s needs, parents were forced to balance a number of equally important demands. Children’s current physical needs had to be balanced with long-term developmental needs and the time constraints of children’s health regimens had to be balanced with the needs of other family members. Both parents and children experienced difficulties in the management of JCA at home, particularly in terms of scheduling and carrying out the requisite range of therapies necessary to treat the physical condition. There was consensus that children’s concordance was poor: children and parents said that children did not ‘do’ exercises or use aids and appliances. Health professionals felt that disease education explaining the benefits of physical therapy would make children more ‘compliant’. In contrast, children felt that there was nothing that anyone could say that would influence their behaviour, particularly in terms of exercise which they viewed as ‘boring’.

During the focus group discussions, children provided insight into the way they conceptualized their disease and its symptoms. For instance, one child viewed arthritis as liquid inside her and wanted to know if it ‘would spread to other parts of the body’; other children described their pain as ‘a circle round my knee’, ‘an achy fuzzy feeling’, ‘like being pressed really hard’ and ‘as though someone is thumping me’.

The core categories reflecting the broad areas where psycho-educational interventions could play a role are depicted diagrammatically in Figure 1.

The experience of psycho-educational interventions: access, availability and content

Children and parents felt that there was an enormous gap between their need for information and the information they actually received. In general, health professionals, voluntary groups and parent-oriented leaflets were cited as their main sources of information, although a video and weekend summer camps were mentioned by a few parents and children. Parents appeared to be the main recipients of educational interventions, the emphasis being on the provision of factual information regarding disease process (e.g. disease pathology, incidence of disease) and hospital attendance as either in-patients or out-patients. A dominant theme across all focus groups concerned the failure of current psycho-educational interventions to address the wider aspects of JCA (e.g. psycho-social impact).

Parents expressed considerable frustration at the poor availability of psycho-educational interventions. The apparent scarcity of child-focused interventions led children to rely on parents for information. Unfortunately, the majority of parents felt helpless and ill-equipped to answer their children’s questions. This situation became particularly fraught as children entered adolescence, a time when many began to ask more questions and to voice their own anxieties about their future. As one parent stated:

Since the hip-replacement he isn’t coping so well mentally... He’s asking me lots of questions about the future and I just can’t answer them.

Accessing information was a major problem. Many parents felt that psycho-educational interventions often came too late after diagnosis and were generally believed to be inadequate. They felt that booklets describing the full spectrum of rheumatic conditions caused anxiety since parents did not limit their reading to relevant sections of booklets but examined ‘everything’. Thus, parents read about other conditions that sometimes had more severe symptoms and a poor prognosis. In the absence of a reliable reference source, several parents consulted library books. These were often outdated and proved more of a hindrance than a help. These views were typically expressed:

We were only given it (educational video) last year. We’d struggled through the hard part, because you do tend to feel like you’re the only one in the world...

The only way you can learn about it is by reading up on it yourself. We’ve had to go to libraries.

In clinical settings, parents reported that they
Fig. 1. Core categories reflecting the potential spheres of influence of psycho-educational interventions in JCA.

were not allowed sufficient opportunities to raise queries or to discuss problems. Children reported that they felt unable to ask questions in clinical settings. They had difficulty in understanding and remembering the verbal information received. Parents believed that health professionals focused their attention on ‘disease activity’ rather than the child as a person or themselves as parents.

They really don’t understand the problems you have at home... The doctors see them for half-an-hour...and examine the joints...but, it doesn’t just affect their joints. It affects them mentally and that’s what we have to put up with.

You sit there and you think ‘Well, I should of asked this and I should of asked that’, but you can’t and it’s another 6 months away before you see the doctor again.

Children and parents believed current interventions to be largely inappropriate and unrepresentative of children’s actual situations. A divergence of views emerged in relation to a video (Southwood, 1993) for children with JCA. Children with relatively mild arthritis and their parents felt that the video was pessimistic and occasionally distressing. Paradoxically, more severely affected children and their parents felt that the same video was overly optimistic. However, there was consensus that showing children talking about their own experiences of JCA helped both children and parents to feel less isolated, and was seen as a major benefit of this particular video. As one parent stated:

The first time he watched it [the video] he got quite anxious because he wasn’t particularly severely affected and he said, ‘Is this what’s going to happen?’ So I went through it and picked out the bits that I thought were relevant.

Children’s comments about the video included:

Well, I haven’t got it in many places so I thought that I was lucky because other people have got it worse.

I thought that it was going to go worse and I’m going to get it in most places. It was like the first time I went in to hospital. There was a load of old people there and mostly old people have it. I don’t know anyone who has arthritis at school, except for a few teachers who have it.
Sometimes I thought, ‘Oh God! I’m the only one that has got it [arthritis] out of all my friends’. Then when I watched the video, I knew that quite a lot of other people had got it other than me.

In general, both parents and children reported that psycho-educational interventions failed to prepare families for the enforced changes that accompany JCA. They felt ill-prepared for the burden of self-management or the associated time commitments. The uncertain and fluctuating nature of JCA was difficult to cope with. Both parents and children felt they would have benefited from being informed that children have ‘good’ days and ‘bad’ days, and can even experience a wide variation of symptom severity within the same day.

The benefits of weekend summer camps hosted by voluntary organizations and paediatric teams were strongly extolled. Several parents felt that this socially orientated intervention was of greater educational value than any written or audio-visual materials and had the advantage of allowing opportunities for discussion with professional experts as well as other parents. Moreover, camps were believed to recognized the fact that JCA affects all members of the family. Illustrative comments included:

Mary’s benefited by groups...like the summer school session and things like that where she’s actually been with children with the same problems.

I ended up crying in a discussion because for 2 years that he’d had arthritis, I’d never spoken to anybody, apart from my husband and the doctor.

Thirst for knowledge
Parents’ and children’s thirst for knowledge appeared to be unquenchable. They wanted to know more about disease management in the home environment, the psychosocial impact of JCA and their children’s future prospects. Parents were particularly concerned about the impact of JCA upon the children’s long-term development and wanted more information pertaining to the side-effects of treatments in order to make more informed decisions. These views are exemplified:

I think it’s right that we’re warned about these things [side-effects], because we’ve got to watch out for them and we’ve got to get on to them quickly.

Children felt that current interventions failed to explain how JCA may affect school life, friendships, social lives and family functioning. More specifically, children wanted to know in advance that they may not be able to participate in Physical Education (PE) or go cycling with friends, they wanted to know that they may be teased or bullied. They wanted to know how they could deal with these situations when they arose. Children were adamant that they should not be shielded from the more negative aspects of JCA and its treatment. As one child said:

I want to know everything.

Children wanted to know why they were taking particular medications and they wanted to be informed of potential side-effects. Children were aware that this knowledge might hinder their initial adjustment, but felt that by knowing ‘everything’, the unpredictable nature of JCA would be easier to cope with in the long term and unexpected setbacks would be less traumatic. Comments included:

I’d like to know what could happen, so you’ve got no surprises later on.

I’d like to know what I was taking them for [tablets]. Not just take them.

Although health professionals were aware of the need to inform children and parents about JCA and its treatment, they advocated a cautious approach. They were concerned that too much information would cause anxiety. Furthermore, they reported that they sometimes did not know how to respond to parents’ requests for information concerning hereditary issues. For example, parents often asked if they had contributed to the development of JCA.
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in their children through genetic or environmental factors.

**Future psycho-educational interventions**

Not only did children and parents call for more interventions in terms of information provision and self-management, but they expressed a desire to educate ‘other people in society’. Parents and children believed that education at a societal level was necessary to inform others of the realities of JCA and would result in increased empathy towards their own situations. For example, the relative invisibility of JCA among some children led to considerable difficulties in terms of lack of understanding and inappropriate expectations.

People should have more information about arthritis in children because they think it’s more older people that get it.

People do not understand how I feel and what the pain is like.

It was felt that other people perceived arthritis as a condition restricted to older adults and failed to appreciate the unpredictability of JCA. Most parents and children reported problems at school, often linked to teachers’ lack of understanding regarding the fluctuating nature of JCA, which can result in a child being unable to walk into the classroom in the morning but able to run and play with classmates in the afternoon. This led to parents and children feeling discriminated against and marginalized. Children wanted others to understand their needs but did not feel able to explain the nature of JCA themselves. Asserting their needs at school was particularly difficult, therefore wider provision of education in society was viewed as a means of removing this burden from children. Several parents, who had attempted to take information into schools had met with disappointing responses.

People don’t understand that one day you can be okay and the other day, that you can’t.

Some of my friends don’t understand that I can’t do things as well as they can.

I would prefer them [friends] to know a lot about it because then they’d know how I feel and they would understand more.

...when I have been playing a lot of games and when I sit out, everyone thinks that I’m doing it because I really don’t want to do any of the games, but, it’s because it’s really hurting me and I can’t.

There was consensus among the children that they were ‘the experts’ and they felt that they should be consulted in the development of psycho-educational interventions for the future. The strength with which children expressed these views was very clearly observable to the focus group moderators. As one child said:

You’ve really got to ask people like us what we want...otherwise you’ve just got a load of people who think they know about arthritis. It doesn’t work... It’s not doing anything for anyone.

In terms of the content of future interventions, consistent themes emerged among children and are exemplified in the following:

Show kids with arthritis and how they cope through the day...

Talk to different people...’cos different people have got different things wrong with them.

...more suggestions about how you cope with it [JCA].

Tell other people...how to treat you and how not to treat you [because other people] treat you as if, ‘Oh! We’ve got to protect her. She can’t hurt herself’, or, ‘She hasn’t to fall over’. They’re constantly making sure that you’re all right and making sure that you’re not hurting anywhere and it’s just really annoying.

Suggestions from parents followed similar themes. The importance of showing positive role models, both for themselves as parents and for their children was viewed as a useful way of holding out hope for the future.
I think what they should have done is show the same child on a bad day and show them what they could be like on a good day so they will see the bad part and then they will know perhaps there’s a light at the end of the tunnel.

The other thing I would find useful is seeing people who have come through it all and are leading a relatively normal life... A lot of times you get to the point where you think there’s just no hope. You’re going down a long tunnel and there’s actually no light at the end of that tunnel. It would be nice to be introduced to people who’ve been through it all and are OK at the end of it... All I see when we come to hospital or clinics are people who aren’t doing very well.

The need for social support was a main theme to emerge among parents who felt that they would benefit from meeting with other parents on a monthly basis. One parent suggested:

We could do with more groups...because I think parents hit a low and you feel very down about it, whereas, if you go to something like that and somebody else has it as well, it helps you accept it.

Discussion

The study has provided a set of useful signposts that can be used as a guide in the development of psycho-educational interventions. The voices of children and their parents were as one in expressing an overwhelming need for greater availability, easier access and more comprehensive psycho-educational interventions in the context of JCA.

Before discussing the implications of findings for future developments, a few caveats need mentioning. The exploratory nature of the study, the purposive sampling technique and small sample size limit generalizability. Furthermore, although from a wide geographic area, all parents and children were attending one regional hospital, and therefore their views may be biased by contact with the same paediatric rheumatology team and their standard educational practices. However, the variation in geographic location suggests that contact with primary health care, educational institutions and social services was more heterogeneous. One limitation of focus group methodology is that the group forum may inhibit some participants from discussing sensitive issues.

Several procedures were adopted to guard the validity of findings. First, the focus groups were conducted by an independent moderator (K. H.). Second, the same set of questions were discussed in each focus group. Hence, the data were generated from three different perspectives on one common topic. Third, the data were verified by participants at the end of each focus group and were transcribed in their entirety by an independent transcriber (V. P.). Data were analysed independently by two researchers (J. B. and K. S.), and revealed a high inter-rater agreement in relation to the main themes and categories. It should be noted that although qualitative research blurs the boundaries between disciplines, as research health psychologists our frame of reference derives primarily from the theoretical and empirical foundations of health psychology. Furthermore our aim was to map key issues of relevance to the development of psycho-educational interventions. Thus, findings were constrained within this set of operational parameters. Analysis of data from a sociological perspective using a grounded theory approach would provide additional insight and understanding into this neglected area. A strength of the study lay in the exploration of the perspectives of children, parents and health professionals. Nonetheless, in order to provide a fuller picture of psycho-educational needs it will be necessary to listen to the views of primary health care providers, educational and social service providers, siblings, and other extended family members.

The implications for the development of future interventions are discussed below under the broad headings of availability, target audience, content and format. These headings are not mutually exclusive. The main themes and categories relating to future interventions are mapped in Figure 2.
Implications for future psycho-educational interventions and their evaluation

Availability
Children and parents wanted relevant information from the point of diagnosis and onwards throughout the course of the disease. Gaining access to information had proven difficult for many parents, particularly in the early stages of disease when they were trying to come to terms with the condition, its management and its consequences. Clearly, greater availability of a range of educational materials and group or individual interventions combined with ease of access will be of paramount importance in the future.

Target audience
There was consensus across all participants that, with a few notable exceptions, existing psycho-educational interventions were designed primarily for parents rather than children. This reflects the situation commonly found in clinical settings. Movement from the traditional passive role to more active participation of the child in medical consultations appears to have taken root and is slowly growing [e.g. (Meeuwesen and Kaptein, 1996)]. Thus, development of interventions specifically targeting children appears timely and long overdue. The need to target children of different ages was apparent. For example, adolescence is a sensitive time that may demand a specific approach addressing the salient issues. Interventions are also needed for parents, siblings and other family members (e.g. grandparents). The parents and children in the present study felt that professionals (i.e. health, social services and education) failed to appreciate their needs, particularly in relation to the psychosocial impact of JCA. Children reported that they were often ‘ignored’ in clinical consultations where they felt that ‘doctors’ talked more to their parents and also that health professionals were interested in the biological expression of JCA rather than the child as a person. Thus, interventions targeting professionals may help to ease the situation for parents and children, and may help to improve communication in clinical
settings. In addition, children and their parents argued for a broader approach encompassing education at societal levels. They felt that greater awareness and understanding of JCA in society would serve to reduce the discrimination many experienced.

**Content**

As may be expected given their realms of expertise, health professionals stressed the medical management aspects more than either parents or children. However, health professionals acknowledged the wider impact of JCA on emotional and social well-being. Hence, there was consensus across all participants that the current emphasis was on presentation of factual information about the disease and its treatment. This emphasis may reflect the domination of health care professionals in the development and delivery of existing interventions. The psychological and social impact of life with JCA were largely ignored but were deemed salient to the realities of life for children and parents. The desire to understand more about the wider impact of JCA and to enhance self-management ability is in accordance with studies of adults with arthritis [e.g. (Barlow et al., 1997b)]. For example, knowing that feelings of anger, frustration and depression are normal reactions can be reassuring, and can help to reduce the sense of isolation that often accompanies arthritis. Equally, raising awareness of the difficulties that may be experienced in social spheres combined with social skills training may assist children in negotiating their way through essential daily activities (e.g. attending school). Children felt that if they were informed in advance about the possibility of being teased and bullied because they ‘look different’ they could begin to develop coping strategies. The onus is on the developers of interventions to identify effective methods of assisting the target audience in coming to terms with JCA, developing a positive approach to coping and resolving emotional difficulties. The last of these appears particularly relevant for parents who expressed feelings of guilt, helplessness and intense isolation. Such feelings were fuelled by parents’ perceived need to adopt a hypervigilant approach to monitoring their child for any change in symptoms or side-effects. Provision of reassuring information and/or support in a variety of formats may serve to reduce the anxiety they clearly experienced. A summary of suggested content areas for inclusion in psycho-educational interventions is presented in Table II.

Results from the present study suggest that the style and content of psycho-educational interventions should be tailored to match broad categories of disease severity (e.g. mild or severe), developmental age and stage in the life course (e.g. child or adolescent). For instance, one video caused initial anxiety among families with mild JCA, whereas families with severe JCA felt the same video to be overly optimistic. Standardized approaches attempting to meet universal needs may be confusing and distressing for individual families who may be cited at differing points on the disease spectrum. Children and parents felt that interventions should aim to balance optimism with realism, thus acknowledging the differential experience of JCA. The needs of children at the milder end of the disease severity spectrum appeared to be particularly neglected. Paradoxically, this group faced more social barriers than children with severe and visible arthritis. It appears that children with mild JCA may be on the margins of two groups of people, those with disabilities and those without. The fluctuating nature of symptoms associated with mild JCA appears to exacerbate the experience of marginalization, causing confusion for the child, their parents and others in the social network. Indeed, the social expectations of others appear to be founded upon times when the child is apparently well rather than when they are obviously ill. Moreover, Wright (Wright, 1960) suggests that people whose disablement is severe have little choice but to accept themselves as disabled. In contrast, people with mild disability who are almost ‘normal’ find it is easier to deny their disablement thus impeding the process of adjustment.
Table II. Content of future psycho-educational interventions

| Essential disease-related information (e.g. aetiology, symptoms) |
| Treatment-related information (e.g. medication, exercise, use of aids) |
| Side-effects of treatment |
| Time commitment needed |
| Psychological and social impact |
| Self-management strategies (e.g. relaxation, cognitive pain management) |
| Assertiveness training for parents and children |
| Communication skills for children, parents and health professionals |
| Social skills training, particularly for children |

Format

There was an overwhelming call for increased interventions in written, individual and group formats. New technologies, such as multi-media computing, may offer a means of meeting specific needs through individualized paths of learning that take account of developmental level and different perspectives. However, it will be important to ensure that the advent of sophisticated psycho-educational media offering individualized access does not perpetuate families’ intense feelings of isolation. Children and parents valued the opportunity to share their experiences with similar others in the focus group setting. Group education, informal support groups, activity weekends and summer camps have the advantage of reducing social isolation and providing much needed social support. The salience of sharing with similar others in a safe, non-threatening environment has been identified as a consistent benefit associated with group education for adults with arthritis (Barlow et al., 1997a), and may offer a much needed source of support for children with JCA and their families. Group education could serve to counteract feelings of being ‘different’, children will belong by virtue of the fact that they have arthritis. Parents suggested that the use of successful role models (i.e. young adults who had achieved their goals) in educational material would assist the process of adjustment and acceptance. The powerful influence of peers could be used positively by featuring adolescent characters in written materials and the use of peer leaders to deliver group education. Finally, parents called for increased opportunities to discuss problems in clinical settings. They felt that being given a leaflet was not sufficient to meet their needs. However, they often felt unable to ask questions in clinical settings. Assertiveness training for parents combined with training in shared clinical decision making may offer a way forward in this regard.

Theoretical framework

Although this paper has an applied focus, the importance of theory cannot be ignored. Indeed, the need to base psycho-educational interventions within a theoretical framework has been emphasized recently by Jackson (Jackson, 1997) and may help to overcome the widely held belief that knowledge alone is sufficient to change behaviour (e.g. promote concordance with exercise). Setting the experiences of children and parents in an appropriate theoretical framework may enhance outcomes in JCA, and help to guide development and evaluation of psycho-educational interventions. One theory that has emerged as a useful framework for the development and evaluation of interventions among adults with arthritis [e.g. (Lorig and Holman, 1993; Barlow, 1998)] is that of self-efficacy (Bandura, 1977, 1986). Self-efficacy may offer a useful starting point for development of equivalent initiatives targeting children and their parents. The basic tenets of self-efficacy theory suggest that providing participants with mastery experience, role modelling, credible sources of information and the skills to re-interpret physiological state in a positive manner will enhance self-efficacy beliefs. Thus participants (child and/or parent) will perceive greater confidence in their
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abilities to control or manage various aspects of JCA (e.g. pain, emotional impact, daily activities). Moreover, these strategies appear to be in accordance with the expressed needs of children and parents revealed in the present study (e.g. use of appropriate role models, mastery experience).

Conclusion

There are no easy solutions to the issues raised by children and their parents, since the feasibility and cost-effectiveness of producing high-quality psycho-educational interventions can often prohibit tailored approaches and widespread dissemination. Nonetheless, exploring the perceptions of children and their families has been valuable in terms of laying the foundations for the development of future interventions. Findings have confirmed that good quality psycho-educational interventions have an important role to play in assisting children and their families in the experience of life with JCA. Moreover, many of the messages emerging from this exploratory study may have relevance for other chronic diseases of childhood. Although the specifics of disease management are likely to vary, the psychosocial challenges faced by children and parents cross diagnostic boundaries. For example, children want to know how to deal with feeling ‘different’, how to maintain their self-esteem and how to manage chronic pain, whatever the cause of that pain or perceived visible difference may be. Support for a non-categorical approach is provided by studies showing that there are more pronounced differences within rather than between disease categories (Stein and Jessop, 1989). Regardless of the target audience, this study has illustrated that consulting the ‘experts’ should help to ensure that the content, style and format is not only relevant, but also salient to children and their parents.

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