PAEDIATRIC RHEUMATOLOGY
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VIEWPOINT

DO PSYCHOSOCIAL INTERVENTIONS HAVE A ROLE TO PLAY IN PAEDIATRIC RHEUMATOLOGY?

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There is a growing body of evidence supporting the effectiveness of psychosocial interventions among adults with arthritis [1–3]. Recognition that such interventions can play an important role in adult rheumatology is reflected in the increasing number of interventions in both hospital and community settings in the UK [4]. In contrast, current provision of psychosocial interventions for children appears somewhat sparse. The purpose of this paper is to discuss the published literature on psychosocial interventions conducted in the context of paediatric rheumatology, and to consider the potential and implications for future provision.

The term ‘psychosocial intervention’ is used to encompass a range of psychological techniques and social skills training designed to alter outcomes by facilitating behavioural change and aiding adjustment. Whether designed for individuals or groups, psychosocial interventions often begin with an educational phase where participants are provided with information about a disease and its treatment. New skills are introduced in accordance with the aims of the intervention and may include cognitive–behavioural therapy (CBT), encompassing a range of coping skills including relaxation, imagery, activity–rest cycling and cognitive restructuring. Interventions with a social component are usually based on a group format and may include problem solving, contracting (goal setting), and communication skills. An interactive format makes full use of group dynamics and contributions from participants, who value exchanging experiences with similar others [5]. A prime example of a group psychosocial intervention for adults is the Arthritis Self-management Programme (ASMP) developed by Lorig et al. [6], which is delivered by lay tutors, most of whom have arthritis and therefore act as appropriate role models for participants.

PSYCHOSOCIAL INTERVENTIONS IN PAEDIATRIC CHRONIC DISEASE

Elander and Midence [7] distinguish three intervention approaches pertinent to paediatric chronic disease.

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The ‘problem-focused’ approach targets behaviour relating to specific medical procedures (e.g. preparation for surgery, dialysis), or specific problems (e.g. pain), utilizing relaxation, biofeedback and behavioural conditioning. The last of these includes techniques such as operant token economy interventions where desired behaviour is rewarded by positive reinforcement, but is withheld if behaviour is maladaptive. The ‘cognitive approach’ aims to produce more general improvements in children’s adjustment, employing strategies such as education and stress management to modify children’s ineffective coping styles and alter maladaptive thoughts about their disease. Finally, the reciprocal influence of the child’s social environment upon their health forms the key to the ‘social approach’, which aims to improve the delivery of care, to increase educational and occupational provision and prospects, and to increase support for carers. There is evidence that these approaches are effective for children undergoing dialysis [8], for a range of chronic conditions (e.g. asthma [9, 10], sickle cell anaemia [11], cancer [12]), and among children experiencing chronic pain [13].

In order to identify published studies of psychosocial interventions in paediatric rheumatology, a comprehensive literature search on MEDLINE, PSYCHLIT and CINLIL CD-ROM systems was conducted. Articles not in the English language and those published before 1985 were excluded. A total of seven articles were identified (see Table I). The heuristic format suggested by Elander and Midence [7] was adopted, thus published studies are discussed under the broad headings of problem-focused, cognitive and social approaches. However, it should be noted that this classification system is not mutually exclusive, interventions are often multifactorial in nature.

‘PROBLEM-FOCUSED’ APPROACHES

Pain management

Chronic pain is a feature of many conditions presenting in childhood chronic diseases. Lavigne et al. [14] and Walco et al. [15] utilized CBT to improve pain management in the context of paediatric rheumatology. Drawing on work with adults, the underlying rationale was to: ‘cognitively distract children away from pain perceptions and reduce subjective pain intensity’ ([15], p. 1075).
### TABLE I
Summary of studies documenting psychosocial interventions for children

<table>
<thead>
<tr>
<th>Authors</th>
<th>Sample Description</th>
<th>Design Description</th>
<th>Intervention Description</th>
<th>Outcome</th>
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<tr>
<td><strong>Pain management</strong></td>
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<tr>
<td>Walco et al. [15]</td>
<td>n = 13 (8 F, 5 M)</td>
<td>Pre-post intervention with 6 and 12 month follow-ups</td>
<td>Eight individual sessions for children introducing cognitive–behavioural self-regulation techniques (progressive muscle relaxation, meditative breathing and guided imagery). Two sessions for parents to review key aspects of behavioural pain management techniques.</td>
<td>Statistically and clinically significant reduction of pain, maintained at 6 and 12 month follow-up. The authors report improvement on functional status at 6 and 12 months, but missing data prevented statistical analyses.</td>
</tr>
<tr>
<td>Lavigne et al. [14]</td>
<td>n = 8 (7 F, 1 M)</td>
<td>Multiple baseline across-subjects design. Pre-post intervention with 6 month follow-up</td>
<td>Children and mothers attended six individual sessions covering cognitive–behavioural techniques (progressive muscle relaxation, electromyogram biofeedback and thermal biofeedback). Mothers were taught operant pain management techniques with special attention given to managing physical therapy and school attendance.</td>
<td>No significant differences for children’s ratings of pain between the immediate and delayed treatment group. Significant reduction of reported pain (children’s and mother’s) from pre-treatment to follow-up. Significant reduction in number of pain-related behaviours reported by mother. No significant reduction of pain as evaluated by physical therapists.</td>
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<tr>
<td>Rapoff et al. [17]</td>
<td>14-yr-old boy with polyarticular onset JCA</td>
<td>Withdrawal (single-subject) design with 9 month follow-up period</td>
<td>Simplified regimen followed by a parent-managed behavioural (token economy) reinforcement programme.</td>
<td>Compliance averaged 44% at baseline and 97% at 9 month follow-up. Clinical improvements noted by rheumatologist and parents. No measures of the child’s rating of symptoms taken.</td>
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<tr>
<td>Rapoff et al. [18]</td>
<td>3 F aged 13, 10 and 3 yr. 2 polyarticular, 1 pauciarticular onset JCA</td>
<td>Multiple baseline across-subjects design with 4 months follow-up</td>
<td>Single home visit where children and parents were taught techniques of self-monitoring and positive verbal feedback in conjunction with the provision of verbal and written information concerning medication, means to increase it.</td>
<td>Compliance increased for two patients from an average of 38 and 54% to 97 and 92%, respectively. Compliance decreased for all three patients at 4 months. The youngest patient had the highest level of compliance throughout.</td>
</tr>
<tr>
<td>Pieper et al. [19]</td>
<td>3 F aged 17, 18 and 11 yr. 2 systemic lupus erythematosus, 1 dermatomyositis</td>
<td>Multiple baseline across-subjects design with 12 month follow-up</td>
<td>Children and parents were taught techniques of self-monitoring and positive verbal feedback in conjunction with verbal and written information concerning medication, possible side-effects, the importance of compliance, the means to increase it.</td>
<td>Compliance improved during the intervention and at 6 month follow-up for all three patients and was maintained for two patients at 12 month follow-up (data were missing for the third patient).</td>
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TABLE I (continued)

<table>
<thead>
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<th>Authors</th>
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<tr>
<td><strong>Social approaches</strong></td>
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<tr>
<td>Stefl et al. [21]</td>
<td>n = 32</td>
<td>Pre-post intervention with 6 month follow-up</td>
<td>5 day summer camp offering children recreational activities and evening educational sessions designed to increase disease-related knowledge and management skills</td>
<td>Children’s locus of control and self-concept significantly improved immediately post-intervention. These positive effects were maintained at 6 month follow-up period, but failed to attain statistical significance. Maximum benefit appeared to be gained by those children (n = 6) who had attended previous summer camps</td>
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<td>Hagglund et al. [22]</td>
<td>27 families</td>
<td>Pre-post intervention with assessments at baseline and 6 month follow-up</td>
<td>3 day family retreat offering 14 h of recreational activities and 14 h of formal educational and therapeutic sessions, addressing issues pertaining to adjustment, coping with chronic illness, enhancing self-esteem, nutritional and gastrointestinal concerns, aquatic exercise therapy and accessing resources</td>
<td>Children’s internalizing behaviour problems were significantly reduced at 6 months. Care givers demonstrated improvements in reports of strain on family leisure and occupational functioning. Mothers’ psychological distress remained stable. Children reported a moderate reduction in their perceptions of current pain intensity at 6 months</td>
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Whilst both studies lend support for the utility of cognitive–behavioural interventions in positively influencing pain perception and behaviour among children, the authors acknowledge difficulties with low response rates, attrition over time and missing data. Furthermore, the use of parametric statistical analyses on small data sets suggests that results should be interpreted with caution. Lavigne et al. [14] expressed concern about the reliance on self-report. However, it is not clear how the essentially subjective experience of pain can be measured by ‘external report’. Assessment of overt pain behaviours (e.g. wincing) can be conducted by external observers, although the nature and frequency of such behaviours will be influenced by the social context, the individual’s style of coping and their pain threshold.

Despite these caveats, both studies indicate that cognitive–behavioural interventions can complement disease management in children. It may be that the interventions succeeded in helping children to feel better able to manage their pain, whilst not necessarily reducing absolute levels of pain. Inclusion of dimensions such as perceived control of pain may serve to clarify this issue.

**Compliance with medication**

Risk factors for non-compliance include disease duration, age, perception of pain and the complexity of treatment regimens (see [16] for a review). Three studies [17–19] examined the potential of psychosocial interventions as a means of enhancing compliance with medication through the use of either behavioural strategies alone, or in combination with education.

These studies provide some support for the potential of psychosocial interventions to enhance medication compliance, although small sample sizes limit generalization. Randomized controlled studies based on larger samples are needed before the effectiveness of such interventions can be proven. In this regard, Rapoff et al. [17] argue for greater multicentre collaboration, since there are few children with juvenile chronic arthritis (JCA) in one location and even fewer exhibiting poor compliance. The precise role played by children in the token reinforcement programme remains unclear, since the interventions relied upon ‘extensive parental supervision’ ([18], p. 440). Hence, results may reflect change in parental compliance behaviour rather than that of their children, who appear to be simply the recipients of pills. One intriguing finding to emerge
was the tendency for patients to overmedicate during the baseline period. In order to gain greater insight into this important issue, it will be necessary to examine compliance from a child’s perspective, particularly in terms of lay representations of disease and its treatment. This approach has proven illuminating among children with other conditions, such as diabetes [20].

‘SOCIAL’ APPROACHES
Acknowledging the complex and multifactorial basis of childhood disease, two studies investigated the effectiveness of multidimensional interventions: a summer camp for children with JCA and a family retreat [21, 22]. To some extent, these interventions encompass both ‘problem-focused’ and ‘cognitive’ approaches. Yet, by recognizing the child’s need for social support and the reciprocal relationship between the child, their family and the social environment, the summer camp and family retreat are social in their approach.

The results indicate the benefits of socially oriented interventions, although it is notable that the camp was conducted over 10 yr ago (in 1984), and in the cultural context of North America where children’s summer camps are the norm. Caution is needed in extrapolating findings to children in other countries, such as the UK, where summer camps for children are less common. Furthermore, the authors point to a number of methodological limitations (e.g. lack of a control group). Nevertheless, these studies indicate the potential of the group experience for promoting psychosocial well-being among children.

THE WAY FORWARD
Although psychosocial interventions do occur in paediatric rheumatology settings, there is a paucity of published studies concerning their effectiveness, particularly in the UK. The documented interventions identified tended to adopt a ‘problem-focused’ approach, targeting specific aspects of the child’s condition, namely pain and medication compliance. The development of psychosocial approaches that recognize the child as a social being are especially called for. There are indications that such interventions are being explored in the UK with the advent of the Into Work Personal Development Programme (IWPD) and the unique Children Have Arthritis Too (CHAT) conference. The IWPD, currently being implemented by Arthritis Care, aims to encourage young people with arthritis to reach their potential in education and employment fields through a comprehensive programme of personal development strategies and employment-related training. Preliminary findings based on process evaluation suggest that the IWPD raises participants’ confidence in their own abilities and encourages them to set achievable personal and occupational goals [23]. The CHAT conference, organized by the concerted efforts of three voluntary organizations, was clearly enjoyed by children and parents alike, although no systematic evaluation was conducted.

A comprehensive needs assessment in the context of paediatric rheumatology would be a valuable resource highlighting priority areas where the benefits of psychosocial interventions could be utilized to the greatest effect. For example, an investigation of ‘additional’ services conducted in Canada [24] found that the most frequently expressed need of children and their parents was for education through newsletters, books and support groups for teenagers. A UK-based study has revealed that parents of children with JCA believe that strategies including greater provision of accurate information, increased opportunity for discussion with health professionals, coordinated service provision, support groups and psychological support would dramatically ease their burden of care [25]. The knowledge gained from needs assessments can improve the congruency between an intervention’s objectives and methods and the needs of participants, thus increasing intervention effectiveness.

Although each childhood chronic condition has unique features dictating specific approaches to disease management, the commonality of experience can 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 perception of difference may be. Arguments for a non-categorical approach to interventions in children and families are supported by studies showing that there are more pronounced differences within rather than between disease categories [26]. Thus, children and parents may learn a great deal from contact with families facing similar challenges, and those equally involved in designing, implementing and evaluating interventions may benefit from adopting a wider perspective.

Future multidimensional interventions may draw more heavily on modern technology. Szer and Stebulis [27] suggest that videos and audio tapes can not only provide a rich source of educational and supportive information, but also represent an infinitely more interesting alternative to written material. A more sophisticated approach to disease education could be realized through the aid of computer technology, with multimedia systems allowing for a wealth of interactive programmes allowing information acquisition at a self-dictated pace. Moreover, such programmes could provide the opportunity for children to test their knowledge and practice skills through game-like formats, thus facilitating feelings of self-efficacy. Indeed, the implications of modern technology for successful disease management are vast, and now more than ever before, there is a real opportunity for providing interventions that are truly multidimensional.

FUTURE EVALUATIONS
A number of methodological issues have been highlighted with respect to the evaluation of psychosocial interventions in children. Firstly, sample sizes tend to be small, thus limiting generalization. The problem of
recruiting sufficient children for larger, randomized controlled studies needs to be addressed before the effectiveness of psychosocial interventions on children’s well-being can be examined systematically. In addition, the development of measuring instruments specific to the needs of children is an essential challenge for researchers in the field. It is noteworthy that not only were all the published studies identified based in North America, but also many of the measuring instruments designed for children were developed in either North America or Scandinavia. Few of these measures have been validated for use among children in the UK or other European countries. Cultural context and the differing systems of health care, which provide the backdrop for psychosocial interventions, need to be considered when examining important issues such as compliance. Equally, cultural diversity may limit the successful transfer of interventions developed in one country to another. However, there is evidence from adult studies suggesting that well-designed interventions can transcend cultural differences [4, 28].

The child is certainly at the heart of treatment strategies operated by paediatric rheumatology teams, thus it is all the more surprising that the child’s perspective is often ignored in research. While parental reports can be useful, only the child knows what it really feels like to have a rheumatic disease in the early stages of one’s life. Greater use of triangulation, using different perspectives (i.e. professional’s, parent’s and child’s) may offer further insight [29–31]. Given the lack of validated measuring instruments and the tendency to ignore the child’s subjective experience, qualitative exploration would seem to offer a useful way forward in the search to improve quality of life for children by ensuring that interventions are congruent with their needs, may help to clarify the impact of interventions, and may illuminate intriguing and unexpected results. Furthermore, the process of participation in qualitative data collection itself offers children the opportunity to share their experiences with similar others [5]. These methodological issues need to be addressed in order that the role of psychosocial interventions can be fully examined in paediatric rheumatology.

CONCLUSIONS

At present, documented evidence concerning the potential of psychosocial interventions in paediatric rheumatology is not extensive. This is largely due to the paucity of studies, a situation that may be partly accounted for by the scarcity of resources available for non-medical therapy. Not only do strategies such as CBT require input from appropriately trained professionals and the paediatric team, but they can be time consuming for all concerned: professional, child and other family members. Thus, adequate funding of non-medical interventions is clearly an issue to be resolved. Furthermore, children are located in geographically diverse areas, thus interventions based on group formats pose organizational challenges. Finally, Lavigne et al. [14] suggest that pain is not always viewed as a prominent issue in JCA. Until such time as psychosocial well-being, including the subjective experience of pain, is accepted as being of equal importance to physical well-being, psychosocial interventions for children will continue to lag behind those for adults. Nonetheless, there are indications that such interventions are promising avenues worthy of greater attention and may have an important role to play in paediatric rheumatology.

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REFERENCES


