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Karen Harrison

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Focusing on arthritis and parenting

NE Foster, MI Wade, K Harrison, JH Barlow

There is little documented information on the experience of parenting with arthritis. A small scale study was designed to gain understanding of the experience of parents who have arthritis, from the perspectives of the occupational therapists and physiotherapists involved in their care.

Arthritis and rheumatological disorders are the largest cause of physical disability in the United Kingdom, with a population prevalence of 8.2% (Badley and Tennant, 1993). These are chronic, painful and disabling conditions, which may have implications for expectations, practice and satisfaction with parenting. However, there is little documented information on the experience of parenting with arthritis. The emphasis of most available literature is on physical disability in general, focusing on the effect of the parent's disability on child development rather than the parenting experience per se (Crist, 1992). Studies reveal that when one member of a family is disabled, the entire family experience the disability in some way, and there is great potential for family disruption (Miller et al, 1983; Ryan et al, 1996). Indeed, the ability of a family to succeed in coping can differentiate those who are incapacitated from those who continue to lead full and active lives in the face of equal or progressive disease severity (Lorig and Holman, 1993).

PARENTS WITH ARTHRITIS

Although it may be assumed that parents with arthritis may be subject to some unique difficulties, very little is known about the nature or impact of those problems or of the solutions which are worked out on a day-to-day basis. Previous studies at Coventry have generated information on these issues from both parents and grandparents who have arthritis (Barlow et al, 1992; Cullen and Barlow 1997). The study reported here is one part of a wider research project which explores the nature and extent of problems that parents with rheumatic diseases experience in the context of caring for children.

Alongside other professions allied to medicine, physiotherapists and occupational therapists have been major contributors in the management of patients with arthritis; in their assessment, treatment and support, as well as prevention of functional impairment. Families have long been recognized as an important variable in the response of patients to therapy (Watson, 1987; Sparling and Sekerak, 1992; Youngblood and Hines, 1992) and therapists have traditionally incorporated the family as a resource for information or by including a family member in the rehabilitation process. Intuitively, it is assumed that during the course of their involvement with these patients, physiotherapists and occupational therapists are made aware of and must work around the difficulties that parenting adds to the patient with arthritis. However, the literature base of these professions appears not to have adequately addressed these issues nor identified the role of these therapists in this context.

PURPOSE OF THIS STUDY

This study extends previous work exploring perspectives of parents with arthritis (Barlow and Cullen, 1996; Cullen and Barlow, 1997). The purpose of the current study was to explore the nature of childcare problems of parents and grandparents with arthritis and the practical solutions to those problems from the perspective of health professionals involved in their rehabilitation. The reasons for the focus on health professionals was to generate new ideas for solutions that therapists might suggest for their patients' difficulties with parenting, and to explore a different perspective than that used previously with parents and grandparents.

It was not the intention of this research to be representative of the problems experienced by

Dr NE Foster is Senior Lecturer in Physiotherapy, **Ms MI Wade** is Senior Lecturer in Occupational Therapy, **Ms K Harrison** is Head of Physiotherapy Subject Group and **Professor JH Barlow** is Professor of Health Psychology and Director of Psychosocial Rheumatology Research Centre, School of Health and Social Sciences, Coventry University, Priory Street, Coventry CV1 5FB

Correspondence to:
Dr NE Foster

patients with arthritis, but rather to gain data which will contribute to therapist and patient information booklets which are currently under development at the Coventry centre.

METHOD

Focus group

A qualitative methodology of focus group interview was utilized. The focus group technique is a method of participatory research which aims to explore the views and experiences of research participants from their own perspectives. Kitzinger (1995) has defined the focus group as: 'a type of group interview that capitalizes on communications between participants in order to generate data'.

The value of this method has recently been reported within a disability research framework (Barlow and Harrison, 1996). A major assumption of the focus group technique is that the permissive atmosphere generates a situation whereby a more thorough understanding of key issues is obtained, contrasting with the normally passive role taken by research subjects when contributing through more traditional methodologies. For more discussion of the focus group technique, readers are directed to Krueger (1994), Kitzinger (1995) and Vaughn et al (1996).

Sample of therapists

Therapists were identified as eligible for inclusion into this study if they were currently involved in the care of patients with rheumatological conditions. They were identified through the clinical interest groups within physiotherapy (Rheumatic Care Association of Chartered Physiotherapists; $n=85$) and occupational therapy (National Association of Rheumatology Occupational Therapists; $n=150$), in addition to local fieldwork educators specializing in rheumatology.

A purposive sample of five physiotherapists and seven occupational therapists gave their consent and were subsequently sent a brief pro-forma questionnaire for completion prior to attendance. The purpose of this was to help focus ideas and to form the basis of the group discussion. Three focus group interviews were conducted; one for occupational therapists ($n=7$), and two for physiotherapists ($n=3$ and $n=2$). The numbers for the physiotherapy groups were very low due to inability of therapists to take time away from their workplace and to the relatively few physiotherapists working in rheumatology within a reasonable distance. The first two meetings were held at the research centre at the university, and the third was held at a physiotherapy department in a participating hospital.

Procedure

On each occasion, participants assembled and the focus group procedure was explained. Discussions covered topics relating to the symptoms and daily impact of arthritis, the role of parenting, and helping strategies which therapists felt to be important. A moderator recorded written notes and supervised an audio recording from a microphone placed at the centre of the group. At the end of the discussion, a summary of results was read back to each group to facilitate verification, amendment and prioritization of data by participants. The interviews lasted 60–90 minutes. Following the completion of each focus group, the audiotapes were transcribed in full.

Several strategies were employed to ensure the validity of the findings:

- Focus groups were facilitated by a moderator
- The same questions and issues were discussed in each focus group
- The data were generated from two different therapy perspectives
- Data were verified by participants at the end of each focus group
- The sessions were transcribed in full by an independent transcriber.

DATA ANALYSIS

The interview transcripts were analysed using content analyses and in order to minimize potential decontextualizing of data, were conducted with reference to the written notes made by the moderator (as suggested by Bertranel et al, 1992; Krueger, 1994). Analysis involved identification and linking of key ideas and emerging themes. This was conducted by two researchers (one physiotherapist and one occupational therapist) and revealed a high level of agreement in relation to main themes and categories. Each transcript was closely examined for participants' quotations which were central to the areas of interest and these were kept intact and can be traced back to the participant and location in the transcripts.

RESULTS

A large volume of data was generated from the three focus group interviews and this paper allows only a brief description of the actual findings. Data on problems and solutions, from both physiotherapists and occupational therapists were organized into the following categories:

- Pregnancy
- Pre-school (0 to 4 years)
- 5 to 10 years
- Adolescent (11 to 15 years)

The data are summarized together in *Tables 1* and *2*. Where appropriate, illustrative quotations are given.

PREGNANCY

i) Problems identified

Issues discussed included the decisions requiring attention before pregnancy (e.g. difficulties with sexual intercourse, problems with pain and fatigue, the use of certain medication which interferes with fertility, cessation of medication or some physiotherapy management).

It was felt that the problems and associated anxiety related to the cessation of antirheumatic drug therapy may exacerbate the problems with pain and positioning for comfortable sexual intercourse. The issues surrounding conception and arthritis appeared complex and the underlying theme was the clear need for more information to fully inform patients (and health-care professionals) before making such difficult decisions.

‘Come back in a month and tell me if you want to take the drug or if you want to try for a baby’.

While it was acknowledged that many patients experience a remission of symptoms throughout pregnancy, therapists discussed the physical difficulties of weight gain, and the associated risk of pain in weightbearing joints and poor posture. Fatigue, a classical symptom of arthritis, was thought to present a major problem, especially if the parent(s) had other children. Participants also suggested that many parents felt anxious regarding the hereditary nature of some conditions, the inability to cope with the upcoming birth and the responsibility of looking after the child.

The ability to achieve suitable positions for childbirth was considered problematic, especially among those patients with hip, pelvis and spine involvement. Several problems were discussed relating to the management and practice of physiotherapy. For example, therapists felt unable to predict which patients were at greatest risk of disease exacerbation and felt some difficulty with balancing appropriate advice regarding their patients’ obstetric and arthritis needs.

Participants also felt that there was a lack of clear guidelines for some methods of treatment during pregnancy. It was suggested that since patients were seen by obstetricians rather than rheumatologists, fewer patients were referred for help with parenting problems.

ii) Solutions identified

Therapists discussed several possible solutions, the first of which was thought somewhat incidental, as many patients experience a remission

TABLE 1. MAIN PROBLEMS IDENTIFIED BY THERAPISTS

Physical impact of arthritis
Treatment regimes (medication, time and contraindications)
Lack of information
Lack of time for discussion
Balancing needs of children with the symptoms of arthritis
Feelings of guilt and loss of role

TABLE 2. SOLUTIONS AND STRATEGIES IDENTIFIED BY THERAPISTS

Improved medication information and choices
Greater quality and provision of information
Coordinated and supportive multidisciplinary team
Support for parents and their children
Access to counselling and psychology services

of their symptoms while pregnant. Improved drug information, and therefore choice, was thought important for parents, in addition to pre-natal and post-natal counselling.

Participants wanted to see an increase in available general information, both in written format and through the use of video. Both physiotherapy and occupational therapy were believed to offer important solutions through appropriate pain management (e.g. transcutaneous electrical nerve stimulation, hydrotherapy, local use of heat and ice), appropriate advice and education (e.g. energy conservation, counselling and pacing). Correct posture and exercises to help relieve discomfort were viewed as fundamental. Therapists felt that a supportive, multidisciplinary team was essential; they discussed their role in informing the obstetric team of patients’ potential physical limitations prior to childbirth and their role in simply ‘listening’.

PRE-SCHOOL (UP TO 4 YEARS)

i) Problems identified

Therapists highlighted that arthritis symptoms often return following birth. The use of certain medication in relation to breastfeeding, comfortable positioning and handling of the newborn were also discussed.

Difficulty with activities associated with ‘normal’ parenting were felt important. These included:

- Changing nappies
- Bathing
- Lifting the child in and out of cots and prams
- Being able to hold and cuddle the child.

Problems with these activities were suggested as having associated, negative implications for the bonding process between parent and child.

The issue of safety was raised, in terms of holding the child, ability to close stair-gates and move rapidly in accident situations. Play, picking up toys and the difficulties of getting down onto the floor were discussed, as well as managing a shopping trolley at the same time as the baby or pram and the difficulties presented by transport (e.g. driving children to various activities, lifting the car-seat and securing it in the car).

The inevitable problem of sleep deprivation was acknowledged by therapists, and in particular the symptom of stiffness, especially with the need to get up during the night to tend to the child. The general mismatch of activity levels between the parent with arthritis and the young baby and toddler was discussed.

‘Your kids are active 24 hours a day and you’re just not’.

On a positive note it was felt that when children reached approximately three years of age, they often become a real asset in helping with practical tasks. Therapists felt that parents with other dependant children experienced additional problems and the notion of considering the parents’ quality of life and children’s activity levels was suggested:

‘Person in their 20s with a couple of little kiddies, with terrible arthritis and nobody would give her new knees and she said: “Look, I want them now, I want my quality of life now; if they fail in 15 years time, whatever,...it is now that I need to be fit and able”’.

In addition, it was suggested that many patients are reluctant to ask for help in parenting tasks. A large portion of the discussion concen-

trated on psychosocial issues, especially the change in roles of parents and children (e.g. small children carrying out activities normally reserved for much older children).

Therapists also discussed the impact of the change in roles of both parents and grandparents who have arthritis (e.g. their expectations of parenthood, inability to do things as ‘normal’ and possibly denial of the problems):

‘Instead of playing or doing things, he was fetching her tablets, fetching her drinks and running up and down the stairs’.

Finally, therapists discussed their difficulties of tackling physical, functional and psychological problems in the limited time available and it was felt that psychosocial issues could be consequently neglected.

ii) Solutions identified

Improved drug information and management was again deemed important, and participants discussed their role in providing information on available benefits, counselling and stress management.

The need for increased availability of help (e.g. with transport) and improved ability to access that help was suggested, with therapists expressing their desire to see a more direct patient referral system. Liaison between the physiotherapist and occupational therapist was thought to be a solution, in terms of obtaining appropriate assistive devices for the patient, and advising on techniques such as:

- Alternative methods for lifting and handling the newborn
- Avoiding pressure on painful joints
- Changing the height of furniture
- Standing the child to change nappies
- Washing the baby on a changing mat or using the kitchen sink
- Adapting pushchairs and cots.

Adequate rest periods and a balance of involvement for grandparents were recommended, in addition to outside help (if financially able), energy conservation and pacing. Therapists felt that one of their key priorities involved encouraging parents to accept help and not to feel guilty, to take rests at the same time as the child and to try to avoid feeling that this ‘rest’ time should be utilized to do other jobs.

PRIMARY (5 TO 10 YEARS)

i) Problems identified

Many problems were thought to revolve around school and transport, such as getting the children ready for school, walking them to school in the

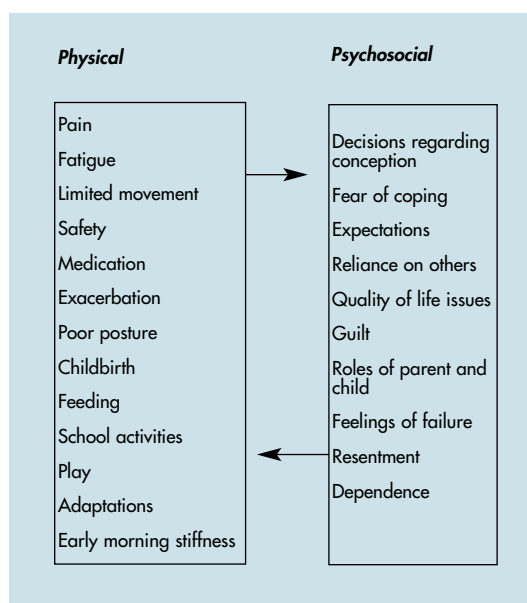


Figure 1. Physical and psychological impact of arthritis on parents.

morning and an inability to get involved with after-school activities. The unique difficulties of single parents with arthritis were discussed, in addition to the difficulty with reciprocation of help from adults.

'...she has only 100 yards to walk to school, it takes her nearly an hour..'

'...they'd have to be pretty special friends to help you all the time when there wasn't anything in it for them. It might work for a week or two, but it is not going to work for ever..'

Teaching the child activities which require fine manipulative skills, such as tying shoelaces or doing up ties, was acknowledged by therapists as difficult for some patients. Additionally, therapists suggested that children find it difficult to understand their parent's symptoms and their general inability to do things as 'normal'.

'...it is hard for them to understand about pain, stiffness and tiredness, they might understand today but they've forgotten about it tomorrow..'

Therapists suggested that, since parents are involved in attending to their children's activities, their own exercise and management programmes may well be overlooked.

Since patients have ultimate responsibility for their own condition, therapists believed that they may often feel lonely and anxious. Interestingly, therapists suggested that some parents with arthritis tended to let issues of discipline with their children slide. Discussions on gender and cultural issues centred around the expectations within different cultures of the wife and daughter's role in the family and differences between urban and rural communities. Also highlighted within this section was the issue that therapists were often unable to provide direct access for their patients and, therefore, symptoms had frequently resolved by the time of appointment.

ii) Solutions identified

Suggested solutions included careful timing or change of drug management, increased help from partners and encouraging parents to communicate their unique circumstances to school staff. Improvement in aerobic fitness through graduated exercise programmes was suggested to help with fatigue. Therapists discussed their changing role within rheumatology, in which more emphasis is placed upon psychosocial aspects of care. Interestingly, participants felt that they needed advice regarding their depth of involvement in psychosocial issues as well as improved provision of psychological support for families.

ADOLESCENT (10 TO 15 YEARS)

i) Problems identified

The problems identified emphasized the psychosocial impact of arthritis such as the merging of roles, or role reversal, within families (e.g. children as 'carers' and parents 'cared-for') and the potential difficulty with associated feelings of guilt. It was apparent that, in some families, teenagers were so involved in a caring role that they failed to cope with their own pressures (e.g. school work).

'Complete reversal of roles,... depending on her children for the first time in her life'.

'...some of the older teenagers can get angry, irritated and frustrated because the mother or father has arthritis...of course, the parent feels guilty..'

The idea that teenage children have difficulty accepting physical adaptations and aids around the home (e.g. tap turners and frames around the toilet) was discussed, possibly resulting in their reluctance to bring friends home.

'...they were so embarrassed by the raised toilet seat that they were always taking them off and hiding them..'

Problems with teenager behaviour and cooperation with tasks around the home were also raised. Therapists suggested that arthritis may restrict family holiday options, especially those involving outdoor pursuits. They discussed parents' fear of coping when the older child leaves home, aging parents with worsening arthritis and the issue of wheelchair acceptance. Therapists highlighted problems with appropriate access to services such as psychology, insufficient numbers of specialists, inadequate resources and coping with the demand of rheumatology patients. In doing so, they also discussed the general lack of support for the adolescent children of parents with arthritis and the notion that therapists' roles are more demanding than ever before.

ii) Solutions identified

Therapists discussed the importance of counselling and education for the whole family (especially the adolescent child) and noted their role within this. The need to improve knowledge of where and how to access help for the family with arthritis was highlighted. It was felt important to increase the patient's control and responsibility for their health through education, while acknowledging the increased demands placed on the therapist. Therapists felt strongly that their role was not to deal only with the reduction of joint range, muscle power

or pain, but also to contribute to the function of the patient in their particular family unit. The need for more specialized, geographically equitable rheumatology services was stressed.

DISCUSSION

The aim of this study was to explore the difficulties associated with parenting in the context of arthritis and to identify possible solutions to those problems, from the perspective of therapists currently involved in the care of this patient group. The health professionals involved provided a rich account of the difficulties and solutions which they were currently aware of and putting into practice.

While some problems were different across the four stages identified, many consistent themes emerged, including practical tasks, such as positioning for feeding, ability to carry safe duties of parenting and the difficulties surrounding school and transport. Many associated difficulties related to the signs and symptoms of specific arthritic conditions and the use of pharmaceuticals.

Pregnancy and the post-partum period

Pregnancy is a period associated with changes in the woman's hormonal environment and is thought to influence the course of rheumatological disease (Fiddler, 1997). The effect of a chronic disease on pregnancy and childbirth and the potential for toxicity both to the fetus and child (via breast milk) from antirheumatic drug therapies has been discussed elsewhere (Fiddler, 1997). It was felt by participants that pregnancy presents uniquely difficult decisions and, while some authors have addressed issues of sexuality (Yoshino and Uchida, 1981; Navon et al, 1982), there appears to be little relevant information which could form the basis of advice for patients.

Participants also highlighted the difficulties which surround the postpartum relapse of disease symptoms and, while 80–90% of patients relapse within 20 weeks, the mechanisms involved are not well understood (DaSilva and Spector, 1992). Some evidence links the onset and prognosis of rheumatoid arthritis with exposure to breastfeeding in susceptible women (Brennan and Silman, 1994; Jorgensen et al, 1994). Clearly, this study has underlined the urgent need for further information to be made available. This study's suggestions regarding fatigue and coping with the demands of a new infant are in agreement with those highlighted previously by Fiddler (1997).

Psychosocial issues

It is apparent from this study that physical difficulties can result in feelings of frustration, guilt and anger with tasks associated with childcare. Of particular note within the focus group interviews was the large emphasis placed by therapists upon psychosocial issues, such as failed expectations, fear, anxiety, resentment, feelings of guilt, changing roles, loneliness and perceptions of both parents and children as 'different'.

This is in agreement with other authors' suggestions that, for parents with a physical disability, meeting the expectations of parenting may be difficult. Reisine et al (1987) found that of 142 mothers with rheumatoid arthritis, 29% felt they did not meet their own expectations in the context of childcare. Kopala and Egenes (1984) highlighted the reluctance of women with disabilities to seek assistance because of fears of being viewed as an 'unfit' parent, and Thorne (1990) drew attention to the conflict between the demands of the social roles of 'mother' and 'chronically ill person'.

Other research on young mothers with arthritis illustrated that feelings of inadequacy in relation to the role of 'mother' is far more painful to accept than feelings of inadequacy in relation to any other role, such as paid work or housework (Geirdal, 1990). *Figure 1* summarizes the reciprocal nature of the physical impact (e.g. limited movement and pain) with the psychosocial and emotional impact of parenting (e.g. fear of coping and guilt) in the context of arthritis.

Included among the suggested solutions to the problems identified were:

- Useful techniques, gadgets and adaptations
- Help from both within and outside the family
- Appropriate and timely interventions (through drug, physiotherapy, occupational therapy and other management)
- A general increase in education and available advice.

Understanding the individual and their family is suggested to support the development of sensitive, personalized healthcare, in which the family can play a more dynamic role (Youngblood and Hines, 1992). Both physiotherapy and occupational therapy can facilitate the development of strategies which help the patient and their families to manage arthritis. Lack of knowledge of available resources, difficulties in accessing help and slow referral of patients posed particular problems for therapists in this study and agrees with the findings of previous work (Cochrane et al, 1990). Pertinent areas for further study include investigations of methods to improve the provision and clarity of information

to patients, communication between health-care regions and the provision of services which meet both the physical and psychosocial needs of parents with arthritis.

Although these findings have implications for further research, they must be interpreted within the limitations imposed by the study design, such as its exploratory nature and small sample. The study does not attempt to provide representation of all therapists since sample recruitment was restricted to those involved in the care of patients with arthritic and rheumatological conditions.

While this was felt to be the optimal method for this study, it is not known if other therapists, drawn from other samples, would have provided different information or emphasized different issues. In addition, this work would benefit from comparison with others involved with this patient group, such as nurses, social workers and general practitioners.

While the focus group method provided indepth information, the qualitative findings reported here will benefit from further validation and replication through the use of more quantitative methodologies (such as the large-scale survey currently being distributed). It is intended that these findings together will contribute to the preparation of information guides for both parents and health professionals.

CONCLUSIONS

The results reported here, in addition to previous work at this centre with parents and grandparents, underline that the experience of parenting in the context of arthritis presents important difficulties which are faced daily by many patients. Attention within the interviews focused upon physical problems, as presented in the clinical and home settings, but much of the discussions centred around psychosocial issues. This work represents a step towards building a knowledge base upon which health professionals can draw, in order to facilitate the parenting process, keeping the family's choices and resources in mind.

BJTR

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KEY POINTS

- There has been little documented information on the experience of parenting with arthritis.
- This small scale study focused on the perceptions of physiotherapists and occupational therapists who treat patients with arthritis.
- Therapists highlighted both physical and psychosocial problems and suggested practical solutions to these problems.
- More information is urgently needed for both patients and therapists about parenting in the context of arthritis.
- This work will contribute to information booklets and further research.