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Published version deposited in CURVE February 2012

Original citation & hyperlink:

Barlow, J.H. and Cullen, L.A. (1996) Parenting and ankylosing spondylitis. Disability, Pregnancy and Parenthood International, volume 16 : 4-

5. <http://www.nsti.org/procs/Nanotech2009v1/6/M72.404>

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PARENTING AND ANKYLOSING SPONDYLITIS

Our interest in parenting stems from our own experiences as mothers with a particular form of arthritis, that of ankylosing spondylitis (AS). We have first hand knowledge of what pregnancy and parenting can involve when coping with the pervasive impact of this condition. As research health psychologists we meet many people with arthritis who have confirmed that parenting, pregnancy and even the decision to have children are crucial issues that deserve greater attention.

There is very little documented information about the experience of parenting in the context of arthritis. Given our inside knowledge, we decided to begin our examination of this issue by focusing on parenting with AS.

Although pregnancy is clearly a topic associated with women, parenting can also involve men. Furthermore, older people with arthritis told us that they should be included in our study since the ability to successfully grandparent can be affected by arthritis in similar ways to those experienced by parents. Thus our study is the first to examine the issue of parenting amongst mothers, fathers and grandparents with AS.

What is AS?

Ankylosing spondylitis (AS) affects mainly the spine and sacroiliac joints, although other parts of the body (e.g. hips, shoulders, knees and eyes) can become involved. The main symptoms of AS are pain, stiffness and fatigue. Gradual fusion, or ankylosis, of affected joints in the spine results in a typical, hunched posture that can restrict physical activities. Moreover, the joints in the pelvic area that move when giving birth,

can also fuse. Ankylosing spondylitis (AS) is one of the few rheumatic diseases to exhibit a male predominance, with reported sex ratios in the region of 3 men: 1 woman. Although the precise cause of AS remains unknown, an association with the antigen HLA-B27 was identified over 20 years ago. Thus there is a hereditary link and this form of arthritis tends to run in families. The onset of AS occurs between the ages of 20 and 35, peak childbearing years, and many mothers with AS report a flare-up of symptoms shortly after giving birth.

Survey of parents and grandparents with AS

Aims and method

The aim of the study was two-fold. Firstly, we wanted to know whether having AS had influenced the decision to have children, and secondly, we wanted to explore the extent and nature of the difficulties parents with AS encounter in caring for their children. We took advantage of having a captive audience at the 20th National Ankylosing Spondylitis Society Symposium held at Coventry University, to distribute brief questionnaires. The response delighted and amazed us. Almost 95% of those attending took the time to complete our questionnaire. This project certainly captured everyone's interest and imagination.

Results

Ninety-six questionnaires were returned giving a response rate of 95%. Of these, 73 (64% men and 36% women) had AS. One respondent was unsure of their diagnosis and the remaining 22 (31.8% male and 68.2% female) were partners. The mean age of respondents with AS was 48

years, and mean disease duration was 24 years.

Decision to have/not have children

For the majority of respondents, having AS did not influence their decision to have children and for some the diagnosis of AS came after the birth of their children, as one participant commented too late. This lady lost her baby 24 hours after the birth. At the time AS was not diagnosed, even though she had experienced symptoms from the age of 10 years, and feels certain that the poor expansion of the pelvic area was a contributory factor to the loss of her child.

A small percentage of respondents reported that the hereditary risk associated with AS had influenced their decision to have children; it gave them reservations. In addition to the hereditary risk, several participants reported fears and concerns about their ability to conceive due to the side effects of their treatment.

During and after pregnancy

Increases in pain and stiffness were experienced by some participants during pregnancy. For others, increase in pain and stiffness came after birth and restricted their ability to lift and nurse their baby.

Parenting difficulties

Parenting difficulties were reported by 38% of respondents. These difficulties were categorised into five stages. As expected, a difference in parenting difficulties between both mothers and fathers is noticeable. For example, mothers with AS experienced more difficulties with babies and toddlers whilst fathers tended to experience more difficulties after their children reached the age of 5.

Birth to 5 years

The main areas of difficulty in caring for babies and young children of less than 5 years of age centred on breast-feeding, lifting, holding, bathing, putting to bed and the playing of physical games and activities. Typical comments were:

My neck is totally fused and I could not see where the child was feeding

I had difficulty lifting without the fear of dropping the children

Children over five years

The main areas of difficulty experienced with caring for older children of 5 years and above centred on the inability to participate in physical games and activities. In addition, the feeling of being extremely fatigued was the most frequently cited symptom causing difficulties in the context of child care. The following comment provides an example of this problem:

Because of fatigue I had a lack of patience to help my children and understand them.

Across all the stages of child care respondents reported feelings of frustration, impatience, anger, irritability and depression. These feelings were typically expressed as follows:

I became irritable due to discomfort and stiffness

Being unable to join in physical activities left me feeling very frustrated

Finally, one respondent suggests:

I let my pain control my anger instead of understanding youthful behaviour.

Conclusions

These preliminary findings suggest that approximately one third of people with AS experience difficulties with parenting which they attribute to AS. Fatigue, limited mobility and negative emotional reactions appear to be the main factors detracting from perceptions of successful parenting in our sample.

RESEARCH

Consequently, many people felt deprived of the joys and pleasures of simply being a parent.

The way forward

The next stage of our research is to gain greater insight into the nature of problems experienced not only by people with AS but also by people with other types of arthritis. We intend to conduct focus group discussions, in-depth interviews and a structured survey.

The information obtained will enable us to describe the problems encountered in greater detail and to begin to collate strategies people have found helpful when parenting in the context of arthritis. The ultimate aim is to produce a Guidebook for parents and to obtain sponsorship for a video featuring parents with arthritis demonstrating their coping strategies and the use of equipment. Only by understanding the extent and nature of the parenting difficulties experienced by mothers, fathers and grandparents or carers with arthritis can we hope to raise awareness of their needs.

Our aim as health psychologists and parents with AS is to find ways to help other people who are facing similar challenges in raising children in the context of coping with a debilitating chronic disease.

The hereditary link for this form of arthritis has resulted in our concern for our children's current and future health status. We tend to monitor our children's every ache and every pain to see if they are developing AS.

Lesley: "Having seen my sister and my brother struggle to cope with AS and raise their children, my main concern has been with the hereditary nature of AS and on the future health status of my children and of my nephews and nieces."

Julie: "The worst times I remember were when I could not lift my daughter Anne-Marie's legs to put the nappy underneath and having to drop her the last 6

inches into her pram because I could not bend over. As Anne-Marie grew older and went to play group it was difficult to explain - and hard for her to understand - why I was unable to give her a welcoming cuddle like other mums. Eventually both Anne-Marie and my second daughter Michelle accepted that I could not always run around with them. I remember them playing around me while I did my daily exercises on the floor in the lounge. Now 14 years old, Anne-Marie straightens my head and spine for me, helping me to maintain my posture. I find my increasing inability to carry heavy bags, open heavy doors and push shopping trolleys very frustrating. However my inabilities provide very positive ways that my daughters can help me. We should not forget that watching someone else close to you experience pain is very difficult, particularly when you do not know how best to help."

We would like to finish this article with the words of a participant in our study, the partner of a lady with AS:

I have struggled to love and keep the family as a loving functional unit. I think I have, and am continuing to succeed. Ankylosing spondylitis changed the woman I married beyond recognition, the adjustments have been very hard, we continue to live and love and I think it's getting better.

If you would like to take part in this project please contact us at the address below.

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