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Long-term follow-up of 246 adults with juvenile idiopathic arthritis: social function, relationships and sexual activity

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Abstract

Objective. To examine social function, relationships and sexual activity in adults with juvenile idiopathic arthritis (JIA).

Patients and methods. Two hundred and forty-six adults identified with long-standing JIA had an average disease duration of 28.3 yr. Specific information was sought on marital status, offspring, age at first sexual encounter, and problems related to disease in sexual activity and pregnancy.

Results. Fewer patients (42.8%) were in stable relationships than their siblings (55.3%). The percentage of patients with children was 27.5. Twenty-three per cent of all known pregnancies ended in miscarriage. Of the women who had had a Caesarean, 78.9% had either reduced hip mobility or short stature. JIA had a detrimental effect on body image in 50.7% of patients but relationships were affected in only 28.2%. The percentage of patients who were sexually active or had had previous sexual experience was 83.3; 58.3% of these had disease-related sexual problems.

Conclusions. A significant proportion of individuals are sexually active before transfer to adult rheumatology care at the age of 18 yr. This highlights the need to introduce sexual counselling in adolescent clinics. The high incidence of psychological sexual problems may benefit from appropriate counselling and training.

Key words: Juvenile idiopathic arthritis, Long-term follow-up, Marriage, Children, Pregnancy, Body image, Sexual activity, Social function.

Adolescence is a time of change biologically, emotionally and socially. Before reaching adulthood, an adolescent has to establish his or her identity, achieve independence from parents, establish relationships outside the family and find a vocation. Body image is important to all adolescents [1, 2] and may be detrimentally affected in juvenile idiopathic arthritis (JIA). Generalized growth failure and pubertal retardation [3] are seen in severe JIA. Some local growth anomalies (e.g. a short digit) are often hidden but may cause inappropriate concern to the patient, whilst other anomalies, such as micrognathia, can profoundly change facial appearance. Drug therapy in JIA may also have detrimental effects. Oral corticosteroids alter the distribution of fat stores and can change skin appearance, with acne and hirsutism. Cyclosporin may also cause hirsutism. Chlorambucil causes gonadal failure, which can have a profound effect on an individual’s perceptions of their sexuality. The scars from previous orthopaedic surgery may also affect a patient’s self-confidence.

The development of social responsibilities may be impaired by an inability to perform household tasks. The avenues an adolescent with arthritis has for rebellion and the consequent development of independent strategies with separation from his or her family can be limited by physical dependence. Limited mobility can affect an individual’s ability to participate in socializing activities [4, 5], leading to loneliness and depression.

Difficulties with relationships may persist into adulthood because of delayed social maturation. If the individual is physically dependent, there will be more reliance on friends and sexual partners to act as carers. Relationships with sexual partners may take longer to establish [6], possibly because the relationship is not...
just partner-to-partner but also potentially carer-to-dependant. However, a number of adults with JIA have long-term relationships with other disabled people [7].

Sexuality includes the adoption of certain gender roles [8]. Society’s definition of masculinity traditionally identifies the male as strong, practical and as the main bread-winner in a family. The corresponding role for a woman traditionally identifies her as a wife, homemaker, attentive mother and, more recently, an income provider. Arthritis may interfere with an individual’s capacity to meet these demands.

Delayed onset of sexual activity is related to poor body image and decreased mobility limiting social activities [9, 10]. The attitudes of society to physical deformity may also affect social interaction. Sexual activity can be adversely affected by arthritis [11, 12], with pain, the fear of pain, fatigue [13], depression and anxiety all potentially reducing libido.

Methods
Two hundred and forty-six adult patients with JIA were asked about social function, relationships and sexual activity at interview. Marital status, pregnancy-related problems and number of children for patients and their siblings were documented. The age of first sexual encounter and sexual problems related to the patient’s arthritis were discussed. Physical function was measured using the UK-validated version of the Health Assessment Questionnaire (HAQ) [14]. The patient’s mood was assessed using the Hospital Anxiety and Depression Scale (HAD) [15]. Their social support network was reviewed with the Short Form Social Support Questionnaire (SSQ6) [16], which measures the number of close supportive social contacts an individual has and the individual’s perceived satisfaction with that support. The perceived handicapping effect of a person’s disease on their relationships, body image or attractiveness and social activity was measured using the Disease Repercussion Scale (DRP) [17], the scores ranging from 0 (no effect) to 10 (maximal effect). Correlations were assessed using Spearman’s correlation coefficient (two-tailed).

Results
Patient demographics
Of the 246 individuals who were interviewed and examined, 70 (28%) were men and 176 (72%) women. The mean age at review was 35.4 yr (range 18–71) and the mean duration of arthritis was 28.3 yr (range 9–71). The mean age at disease onset was 7.1 yr (range 0.8–15.9). The functional and psychosocial questionnaires were completed by 231 (94%) patients. The frequency of JIA subsets [18] in the study group compared with a paediatric JIA population was skewed towards those subsets with a poor functional outcome [19].

Descriptive information on marital status
The percentage of single patients was 48.6, which was 12.9% higher than that for their siblings. The percentage of patients who were married or cohabiting was 42.8, 10.7% lower than that for their siblings. Patients married less frequently than their siblings between the ages of 15 and 25 (8 vs 25%) and between 25 and 35 yr (48 vs 53%), but married more often than them between the ages of 35 and 45 yr (30 vs 12%). In later life, some siblings continued to marry for the first time, but after the age of 55 yr none of the study group had entered a new stable relationship.

Pregnancy and children
Thirty-two per cent of patients had either been pregnant (30.5% of women) or been responsible for a pregnancy (35.7% of men). The percentage of patients with children was 27.5, with an average of 1.7 child per family. Twenty four per cent of all pregnancies resulted in abortion, 5.6% of them due to termination of pregnancy. Women with psoriatic JIA had a significantly higher incidence of miscarriage (33%) than the other groups (11%), although the numbers were small. This has not been described previously in psoriatic arthritis [20], although a similar miscarriage rate has been reported in psoriatic women receiving UV-A radiation (PUVA) [21].

Caesarean section delivery is often necessary if hip abduction is significantly limited or if there is fetopelvic disproportion because of a small pelvis. For the 114 pregnancies that went to term, 26 infants (22.8%) were delivered by Caesarean to 19 women. Thirteen (68.4%) of these women had limited hip abduction and seven women (36.8%) were below the third centile for height.

Social function
The SSQ6 mean number of social supports was 4.1 (s.d. 1.99). Although the number of people giving support correlated weakly (P = 0.01) with satisfaction, satisfaction was high, with a mean value of 5.25 (s.d. 0.85) from a possible maximum score of 6. Satisfaction with social support was closely related to both body image (P < 0.005) and relationships (P < 0.001).

Using the DRP, 50.7% of patients felt that their body image or attractiveness had been affected by their arthritis, with a mean score of 3.4. The percentage of patients who felt that their relationships had been negatively affected by JIA was 28.2, with a mean score of 2.1. The percentage of patients who had reduced social activity was 56.8, with a mean score of 3.9. In all areas, patients who felt that there was an effect from their arthritis tended to feel that this effect was larger. Body image and social activity correlated significantly with JIA subsets, oligoarticular JIA being associated with fewer problems with attractiveness (P < 0.05) and social activity (P < 0.05). Conversely, systemic JIA was associated with patients feeling less attractive (P < 0.05) and having more problems with social activities (P < 0.05). There was also an association between height and social activity (P < 0.005), but no effect from micrognathia and other growth
defects. Physical disability (HAQ) had an effect on body image \( (P = 0.001) \), social activity \( (P < 0.001) \) and relationships \( (P < 0.01) \).

**Sexual activity**

Of all patients, 83.3% were sexually active at review; 7.1% of patients were active before the age of 16 yr and 37.6% before transfer to adult rheumatology care at the age of 18 yr. The mean age at first sexual experience was 19.3 yr (S.D. 3.9), the mean age in the general population being 17.0 yr. Onset of sexual activity (defined by penetrative intercourse) was similar in men and women (Table 1). Systemic JIA patients had their first sexual experience significantly later and oligoarticular JIA significantly earlier than the study group. There was no variation in the proportion of individuals who were sexually active within each subset. Physical disability (HAQ) correlated strongly with a delay in sexual activity \( (P < 0.005) \).

Those patients who were not sexually active had higher levels of physical disability (HAQ) \( (P < 0.005) \) and a poor body image \( (P < 0.05) \). There were no associations with anxiety or depression scores, gender, social contact or social satisfaction and disease subtypes.

**Sexual problems**

Of patients who were sexually active, 58.3% experienced difficulties related to their disease (Fig. 1). The majority of adverse effects were related to the physical effects of arthritis, pain and physical restriction, which together accounted for 54.6% of difficulties encountered. However, a significant minority of patients experienced body image or self-confidence problems. Less frequent problems included teratogenicity concerns, worries about offspring inheriting JIA, and azoospermia.

In patients who were not sexually active, 30% felt that this was due to their disease. Physical disability accounted for just 8.3% of these; 66.6% of the problems were related to body image. Twenty-five per cent of individuals felt they were not perceived as sexual beings. A male university undergraduate reported that his female friends treated him as if he were ‘one of the girls’.

**Discussion**

Ostensen and Almberg [22] found no differences in age at menarche or age at first pregnancy in comparison with the normal population. There was a higher rate of spontaneous abortion, menstrual disturbances, pelvic inflammatory disease and ovarian pathology. Peterson et al. [23] found no variation between controls and a cohort of 44 JIA sufferers in rates of marriage, divorce, pregnancy or miscarriage. The percentage of women patients who had been advised by their physicians against becoming pregnant was 12.9 compared with just 1.4% of the age-matched controls. Musiej-Nowakowska and Ploski [24] described good outcomes for pregnancy in the oligoarticular JIA group with pregnancy-induced amelioration of disease activity, but post-partum flare in 52%.

Individuals in the study group were more likely than their siblings to be single and living outside a stable partnership. The proportion of patients married to date is lower, but individuals with JIA may be deferring marriage to ensure that their partner is the right person to also become a potential carer. Deferred marriage is suggested by the fact that few patients married before the age of 25 yr, but a high number of patients enter a stable relationship between the ages of 35 and 45 yr.

The number of individuals becoming pregnant was lower than in comparative cohort studies and the general population. There were fewer individuals in a stable relationship, which may have had an effect on the total number of offspring. The disability in the study group may have reduced the number choosing to have children. There was also infertility due to early menopause or azoospermia, but this occurred in only a small proportion of the study group and there was a minimal effect on the number of pregnancies. The reported miscarriage rate was comparable to that in the general population.

Early liaison with the obstetrician is important, particularly in view of the high proportion of patients with either poor hip abduction or small stature who had their babies by Caesarean section (78.9%) and who had either poor hip abduction or short stature.

The level of satisfaction with an individual’s social support was high. The majority of patients thought

![Fig. 1. Proportions of problems experienced by sexually active individuals.](image-url)
their arthritis had a negative effect on their body image. Objective measures of physical deformity, such as growth defects and short stature, were not related to the perception of unattractiveness, which was most strongly related to poor physical function. This suggests that those individuals who find physical difficulty in social interaction have the poorest perception of their own attractiveness.

The majority of patients, though experiencing high levels of disability, were sexually active. Despite a slightly older age at first sexual experience, a significant minority of patients became sexually active whilst still under the care of a paediatric rheumatologist. As potentially teratogenic drugs are increasingly used in the paediatric population, the need to address contraception in adolescent clinics becomes essential. Sex education is frequently inadequate for young adults in the general population and issues around disability and arthritis should be discussed with an open attitude and without embarrassment. Educating arthritis patients about pregnancy and delivery of a baby may relieve concerns related to a lack of knowledge. Awareness that psychological influences play a part in sexuality and sexual problems, together with advice about the physical aspects of lovemaking with disability, should be introduced to the adolescent with JIA.

Although the majority of sexual problems were related to physical disability and pain, there was a high incidence of psychological problems concerning self-confidence and perceived attractiveness. It should be possible to address the psychological areas of difficulty with appropriate advice, counselling, and self-esteem and assertiveness training.

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References