Long-term follow-up of 246 adults with juvenile idiopathic arthritis: education and employment

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Abstract

Objective. To examine the levels of education and employment in adults with juvenile idiopathic arthritis (JIA) compared with their siblings and national figures.

Patients and methods. Two hundred and forty-six adults identified with long-standing JIA had an average disease duration of 28.3 yr. Educational achievements and employment status were recorded and comparative data obtained from siblings and the National Office for Statistics, UK. The effects, incidence and nature of discrimination in the workplace were also explored.

Results. Across all levels of education the study group achieved significantly better results than both the national average and their siblings. In contrast, the rate of unemployment in the patient group was more than twice that in the national population. The percentage of patients who had encountered discrimination in the workplace was 25.1.

Key words: Juvenile idiopathic arthritis, Long-term follow-up, Education, Employment, Discrimination.

Juvenile idiopathic arthritis (JIA) can have a detrimental effect on both schooling and transition into employment [1, 2]. A successful transition from school to work is one of the most important tasks for all adolescents and is particularly difficult for those with chronic illness or disability. Social attitudes towards disability may be as important as disability itself. Many parents and professionals perceive school-aged disabled people as ‘children forever’ rather than future adults, and do not always consider competitive employment as a realistic goal for handicapped children. Other areas that may cause difficulty include [3] a lack of knowledge about career advice for the disabled, practical difficulties in attending work regularly for those with chronic disease, and poor self-advocacy skills.

Ansell and Wood [4] found that 83% of 243 patients were in education, employment or married and running a home at 15 yr follow-up. Miller [5] followed up 44 patients for an average of 16.1 yr and showed that patients received a similar level of education to their siblings and the local population. Poor physical function was more common in those adults staying in education and becoming ‘homemakers’, compared with those entering the workplace.

The employment rate tends to fall with longer follow-up periods. Foster et al. [6] found that 21% of 180 patients at 18.7 yr follow-up were unemployed despite good academic attainment. David et al. [7] studied 43 patients with a mean disease duration of 19.7 yr. In this group 30% had not passed any formal examinations, 42% had received O-levels and 21% had attended university. Sixty-six per cent of patients were employed but 30% were not working as a direct result of their disease. Peterson et al. [2] reported, in a cohort study performed on 44 patients with an average follow-up of 24.7 yr, that the patients had similar educational achievement to controls but a significantly lower level of employment (70.5 vs 87.3%, $P=0.015$); however, only 3/13 attributed their unemployment to their arthritis.

Appropriate vocational planning and support can facilitate the transition from school to work in adolescence. White and Shear [8] reviewed a group of 242 patients (72% with JIA) who had been given specific prevocational assistance. They reported an employment rate of 72%, and 15% of patients continued to attend university. The unemployment rate was just 6% whilst 6% were full-time housewives and mothers. Fewer than 2% with any educational achievement were unemployed. Twenty-seven per cent completed university compared with just 7% of the control population.
Methods

The educational achievements and employment status of 246 adult patients with JIA was documented at interview. Data from the National Office for Statistics, UK were also reviewed to determine rates of employment and education in the general population, to act as a control group. Comparative data were also collected on patients’ siblings to be used as a control group.

Educational information was gathered on whether the patient went to a mainstream school, a school for the physically disabled or a combination of the two. The level of national educational qualification achieved and time in education was documented. A full employment history was taken and included the social class of the employment and reasons for a change in employment. Unemployed patients were asked whether they attributed their unemployment to the effects of their arthritis. The incidence, nature and effects of discrimination in the workplace were also explored.

Correlations were assessed using Spearman’s correlation coefficient (two-tailed). Candidate predictive factors were initially assessed using a matrix of Spearman’s correlation coefficients. Those factors with significant correlation coefficients (\( P < 0.05 \)) were entered into a multiple linear regression analysis.

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 yr). The functional and psychosocial questionnaires were completed by 231 (94%) patients. The frequency of JIA subsets in the study group, compared with a paediatric JIA population, was skewed towards those subsets with a poor functional outcome [9].

Descriptive information on education

The percentage of patients who attended a mainstream school only was 79.9 (mean length of stay 9.5 yr, s.d. 2.9 yr). Two per cent attended a school for the physically disabled only (mean length of stay 10.5 yr) and 18.1% attended a combination of mainstream and specialist schools (mean length of stay in specialist school 4.5 yr).

Across all levels of education from GCSEs and A levels to postgraduate degrees, the study group achieved better results when compared with both the national average and their siblings (Fig. 1). The number of pupils leaving school without any formal qualification was only 11%, almost half the figure for the general population. The number attending a university or similar establishment was 34.8% compared with 20.5% nationally.

Descriptive information on employment

In contrast to the good examination results, our study group were more likely to be unemployed than the national average (Fig. 2). As would be expected in a physically disabled group, the incidence of manual work (8.2%) was much lower than in the control groups. Conversely, the number of patients in white-collar non-manual work was slightly higher. The number of patients entering a profession was similar to those for both of the control groups. The percentage of unemployment in the patient group was 137% higher than in the national population.

Of the patients who were not in work, 88.5% attributed their lack of occupation directly to disease-related problems. Thirty-two per cent had never worked. Fifty-nine per cent had worked for a variable period in class III white-collar jobs. The time in employment before leaving work due to disability was 10.8 yr (range 1–41). None of the patients who had entered a professional career had subsequently become unemployed. Unemployed patients had significantly higher levels of disability than their employed peers [average Health Assessment Questionnaire (HAQ) score 1.89 vs 1.02, \( P < 0.001 \)].

The percentage of all patients claiming the care component of the disability living allowance was 43.8. The percentage was 78.3 in the unemployed group. Similarly, 12.3% of patients claimed incapacity benefit, rising to 43.5% in the unemployed group.

Descriptive information on discrimination

The percentage of patients who had encountered discrimination was 25.1 in the workplace and 26.5 in a social setting. Discrimination could be overt, with
descriptions from patients such as ‘I was told I shouldn’t work as I was taking an able-bodied person’s job’, but was often covert. The forms of discrimination included problems at job interviews (45%), being passed over for promotion or sidelined into less fulfilling work (26%), and unresolved problems around access to the workplace (15%).

Predictive analysis
The best model of forward stepwise multiple regression analysis identified four categories of variables that independently made a significant contribution to unemployment (Table 1). The most important predictor for unemployment was the educational level achieved by the patient. Physical disability as measured by the HAQ [10] and the presence of poor (denial and dependent) coping strategies, using the London Coping with Rheumatoid Arthritis Scale, which separates individuals into those who cope by denial, passivity, openness and dependence [11], had moderate effects on unemployment.

Discussion
The majority of children with juvenile arthritis are managed within regional units and benefit from mainstream education. The attitude of the general population and the potential for discrimination may be beneficially affected by the exposure of able-bodied children to the disabled population.

JIA sufferers have a high level of educational achievement, a high proportion of patients gaining university degrees. Successful education eases the transition from education to employment, which is closely related to the highest education level attained ($P < 0.001$). Patients who have a degree of physical impairment may be less distracted from their studies by physical activities than their peers. If patients are able to enter a profession (class I) there appears to be less impact from their disease. No-one in a professional career had to leave work because of their disease.

Using siblings as controls initially appears to suggest that the presence in the family of a child with JIA improves the educational achievements of the other children. This effect may be related to patients (and their siblings) who attend a tertiary referral centre being more likely to come from more privileged backgrounds than those who are seen in less specialized centres.

Poor school attendance in ill children and periods of hospitalization or tuition at home can lead to a decline in educational progress [12]. The effects of home tuition inevitably involve a degree of social isolation of the child from his or her peers. In this study, the number of close social contacts was significantly higher in patients with higher levels of educational achievement ($P < 0.001$) and also in patients educated solely within mainstream schools. The level of satisfaction with social support was higher when individuals were mainstream-educated ($P < 0.05$). The level of disability (HAQ score) did not appear to adversely affect satisfaction with social contact.

Despite being a well-educated group, unemployment was much higher in the patient group. The majority of patients without work attributed their unemployment to the disabling effects of their disease. Physical disability was not as severe in employed patients as in those without work. The 6.5% of unemployed patients who had never entered the workplace tended to be less disabled than the 21.7% of patients who could no longer work. This suggests that the factors that govern successful transition from education to employment are not solely related to physical ability. The predictive factors for unemployment were not only educational achievements and physical function but also the presence of poor coping strategies. This suggests that an individual’s ability to successfully cope with their arthritis has a large impact on their success in the workplace.

Depression occurs in 23.3% of patients at some time [13] and occurs most frequently in JIA patients in their late teens or early twenties, the period during which they are trying to enter the workplace. There is a significant link between previous depression and unemployment ($P < 0.001$). Previous depression was particularly prevalent in those who had never worked, being present in 87.5% (14/16). Again, this suggests the importance of psychological health during the transition period between school and work.

Unemployment impacts upon the financial security and independence of an individual. There is also a cost implication for society, patients who become more dependent upon the state requiring more financial support. The majority of state support is related to the increased disability in the unemployed group, which necessitates a higher level of care and mobility support. However, a proportion of these costs would fall if patients were able to return to employment.

Over a quarter of patients felt that they had been discriminated against at work. Discrimination is by nature subjective, enmeshed irrevocably with the perceptions the patient has of the environment they live in. If an individual feels he or she has been discriminated against, it does not necessarily follow that the events leading to that perception were discriminatory. Conversely, the unthinking actions of others may amount to discrimination by omission.

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<th>Table 1. Predictive factors for unemployment in adults with JIA</th>
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<td>Percentage of variance predicted</td>
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<td>Patient educational achievement</td>
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<td>Function (HAQ)</td>
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<td>Denial coping strategy (group 1)</td>
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The majority of workplace discrimination occurred around job interviews, with problems equally split between failure to be interviewed initially and a perception of unreasonably high levels of failure once interviewed. Once in work, discrimination was a more covert problem, with access problems and delays in promotion predominating. Only a small proportion (6%) had experienced overtly negative or discriminatory attitudes towards them, usually from direct superiors.

There should be a focus on careers in adolescent rheumatology clinics, with opportunities to have contact with specialist careers advisers. Assertiveness training, interview techniques and attempts to address the psychological needs of the individual would improve their chances in the competitive job market. In adults there is a need for continuing lobbying against discrimination at work through bodies such as the Arthritis Research Campaign and Arthritis Care, and with politicians.

Acknowledgements

This research was supported by a grant from the Arthritis Research Campaign.

References