The dental attitudes, knowledge and health practices of patients with Juvenile Idiopathic Arthritis


ABSTRACT. Aim To investigate the dental attitudes, knowledge and dental health practices of children and adults with a previous diagnosis of Juvenile Idiopathic Arthritis (JIA). Study Design A self-completion questionnaire. Methods Ninety-one children and 82 adults with JIA were age and gender matched with 152 healthy controls. For those below the age of 16 years, the parents’ attitude, knowledge and dental health practices were investigated by the questionnaire. The adult subjects and controls completed an identical questionnaire assessing their own attitude, knowledge and dental health practices. Results Response rates of 84% and 75% were achieved for the subject and controls respectively. Both groups responded similarly to questions assessing perception of different medical conditions. The majority of respondents thought leukaemia was a very serious condition. Twenty-seven percent of subjects and 34% of controls felt dental decay was ‘slightly or not serious’. Ninety percent of subjects and 93% of controls knew having sweet snacks during the day would harm teeth, but fewer were sure that eating sweet foods at mealtimes only would help reduce decay. The majority of respondents (63% and 56% respectively) did not know whether children should receive fluoride tablets but the majority of subjects in both groups had attended a dentist within the last year. Statistics Descriptive analyses and chi-squared analysis were undertaken. A p-value of ≤0.01 was taken as strong evidence of a difference between groups. Conclusion The perception of health and illness by both groups was appropriate. The questions investigating dental knowledge revealed understanding of the basic messages of prevention of dental disease, but finer detail appeared less well understood. Responses concerning dental health confirmed positive attitudes towards good dental health habits. The benefits of brushing with fluoride toothpaste were known, and the majority toothbrushed daily and received dental care within the previous year.

KEYWORDS: Oral health, Dental health, Juvenile Idiopathic Arthritis.

Introduction
Juvenile arthritis is a clinically diverse range of diseases of unknown aetiology, many of which are clinically and genetically distinct from chronic arthritis in adults [Petty et al., 1998]. Juvenile Idiopathic Arthritis (JIA) is relatively recent terminology replacing previous ones such as ‘juvenile chronic arthritis’ and ‘juvenile rheumatoid arthritis’. Many children will have spontaneous remission, but at least one-third proceed to either ongoing active disease into adulthood or have significant morbidity from the sequelae of previous inflammation [Wallace, 1998].

It is not routine for patients attending rheumatology clinics to be encouraged to seek dental care. Furthermore the provision of specialist dental care for this group of compromised patients is not usually facilitated by the involvement of dental professionals in the multidisciplinary approach to their medical care.

The oral health status of patients with chronic, debilitating disease may be poorer than that seen in healthy individuals and this disparity has been reported in paediatric patients with various chronic medical conditions [Roberts and Roberts, 1981; Sheehy and Roberts, 2000; Nunn et al., 2001]. From previously published work from this project [Welbury...
Barriers to care have been suggested as being important in patients with medical conditions such as JIA [Saunders and Roberts, 1997; Walton et al., 2000]. These barriers could include knowledge, fear and access to care. It appears from the literature that the effect of such barriers upon JIA patients has not yet been explored.

The aim of this study was to investigate the knowledge, attitudes and dental health practices of the families of children with JIA and adults previously diagnosed with JIA. The questionnaire survey formed part of a larger study of JIA patients [Welbury et al., 2003] and was based upon the methods employed in a previously reported questionnaire survey of the parents of children with congenital heart defects [Saunders and Roberts, 1997].

**Materials and methods**

Paediatric subjects for this study, which had previously received ethical approval from Newcastle and North Tyneside Ethics Committee, were recruited from paediatric rheumatology clinics and similarly adult subjects from adult rheumatology clinics based at the Royal Victoria Infirmary, Newcastle upon Tyne and neighbouring hospitals. The control patients were healthy dental patients who were age (within one calendar year) and sex matched. These patients were recruited when attending Newcastle Dental Hospital for routine care. The present study formed part of a larger study designed to assess the oral health status of patients with JIA. Informed consent was obtained for all participants. Each adult subject (older than 16 years of age), or a parent of a child subject (younger than 16 years of age), was invited to complete a written questionnaire for which consent had already been obtained.

Subjects and controls also underwent an oral examination including an assessment of caries experience, level of oral hygiene and gingival health. The findings from the oral examinations are reported elsewhere [Welbury et al., 2003].

**Questionnaire Design.** The self-completion questionnaire survey comprised 82 separate questions formulated to identify the attitudes, knowledge and dental health practices of the parents of children with JIA and adults with a previous diagnosis of JIA. Answers were invited using true/false responses or 5 point Likert response scale. There were also questions with several possible answers and respondents were invited to tick those responses most appropriate to them. Some questions were asked twice using different wording and answer format. During self-completion of the questionnaire, a research nurse was available to provide explanation where appropriate.

**Data handling and statistical analysis.** Statistical analysis was undertaken using SPSS for windows.
Simple descriptive statistics were calculated. Responses from cases and controls were compared using a chi-squared test. A \( p \)-value of \( \leq 0.01 \) was accepted as strong evidence of a difference between cases and controls and a \( p \)-value of \( \leq 0.05 \) as indicating a result that is potentially of interest, particularly when the direction of the effect is consistent with other responses.

**Results**

The response rate from the subjects involved in the primary study was good (172/205) at 84%. The response rate for the controls was acceptable 75% (153/205) [Chapple, 2003]. Not all of the questions were answered by all respondents, for example those adult controls who did not have children were unable to answer questions specifically designed for parents. The study and control groups were matched for age and gender. The mean age of the subjects who responded to the questionnaire was 18.6 years (range 1-67 years). The mean age of the controls responding to the questionnaire was 20.5 years (range 3-56 years). The 91 children with JIA had a mean age of 6.4 years. Their controls had a mean age of 9.4 years. The adults with a previous diagnosis of JIA had a mean age of 28.3 years and their controls, a mean age of 29.6 years.

Conforming to the broad areas the questionnaire sought to investigate, descriptive data (comparing subjects with controls) for the following subject areas will be presented.

- Perception of health and illness.
- Knowledge of prevention of dental disease.
- Attitudes towards the prevention of dental disease.
- Dental health practices.

**Perception of health and illness.** There was no significant difference in perception of the seriousness of a range of conditions between subjects and controls. When asked to rate the seriousness of leukaemia, 100% of subjects (172) and 99.3% of controls (152) thought it an ‘extremely serious’ or ‘very serious’ condition. Whereas when asked how serious dental decay was only 31.4% (54) of subjects and 26.2% (40) felt it was ‘extremely serious’ or ‘very serious’. For further comparison, a fractured arm was felt equally by both groups to be less serious than dental decay. When asked to rate the level of severity of their child or themselves (if an adult) having a tooth extracted, 73% (124/170) of subjects and 62% (90/146) of the controls felt that this was only a ‘slightly serious’ or ‘not serious’ occurrence. Having a tooth extracted was classed as ‘extremely serious’ or ‘very serious’ by only 8% (14/170) of subjects and 18% (26/146) of controls.

Table 1 shows the respondents’ ratings for the level of severity of dental decay compared with tooth extraction. These data show that in both groups dental decay itself is rated as more serious than a tooth extraction.

**Knowledge of prevention of dental disease.** When challenged with the statement ‘getting bad teeth cannot be stopped’, and ‘having sweet snacks during the day doesn’t harm teeth’, it can be seen from Table 2 that the majority of respondents thought these statements to be false.

Ninety-nine percent of subjects (170/171) and 98% of controls (150/153) agreed that brushing helps keep gums healthy and 94% (162/172) of subjects and 87% (133/153) of controls agreed that tooth brushing stops dental decay. Less polarised answers were obtained from the statements ‘brushing teeth after eating sweet things will stop decay’ and ‘eating sweet things at mealtimes only will help reduce decay’ (Table 3).

From the latter statement, using the chi-squared statistic, a significant difference (Chi-squared = 5.92, \( df = 2 \), \( p = 0.054 \) was seen for responses between the subject and control group. Sixty-seven percent of

<table>
<thead>
<tr>
<th>Statement</th>
<th>Group</th>
<th>Serious</th>
<th>Not serious</th>
<th>Totals</th>
<th>( p )- value</th>
</tr>
</thead>
<tbody>
<tr>
<td>“How serious is dental decay?”</td>
<td>Subject</td>
<td>73% (125)</td>
<td>27% (47)</td>
<td>172</td>
<td>0.64 (NS)</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>66% (101)</td>
<td>34% (52)</td>
<td>153</td>
<td></td>
</tr>
<tr>
<td>“How serious would it be if your child had</td>
<td>Subject</td>
<td>27% (46)</td>
<td>73% (124)</td>
<td>170</td>
<td>0.92 (NS)</td>
</tr>
<tr>
<td>a tooth extracted?”</td>
<td>Control</td>
<td>38% (56)</td>
<td>62% (90)</td>
<td>146</td>
<td></td>
</tr>
</tbody>
</table>

NB: 5 point Likert Scale collapsed down to dichotomous score. Percentages may not equal 100% due to rounding.

NS = not statistically significant
subjects (115/171) and 62% of controls (95/153) agreed that avoiding sugar altogether is the best way to prevent decay.

**Attitudes towards prevention of dental disease.** As seen in Table 4, the majority of respondents were unsure whether children should have fluoride tablets with very few answering yes to the question ‘do you think children should have fluoride tablets?’ However, the majority of respondents felt that ‘good dental habits will work to stop decay’ with agreement of 95% (147/155) and 94% (113/121) in both subjects and controls respectively. All parents gave their children sweets, although sweets on a daily basis were only given by 25% (37) of subjects and 20% (22) of controls answering the question. Similarly, when asked whether they controlled the amount of sugar their child ate, 76% of subjects (120/158) and 80% of controls (96/120) responded ‘yes’.

When respondents were asked ‘why do you brush your teeth?’ the commonest responses were:
- ‘To keep gums healthy’;
- ‘Help not to get decay’;
- ‘To keep teeth clean’.

**Dental health practices.** All adult respondents had visited a dentist previously, but the frequency or duration since their last attendance was not investigated further.

Ninety-five percent of children (138/145) in the subject group and 98% (104/106) in the control group had visited a dentist. When questioned further and asked to respond in more detail (did they last see a dentist within 6 months; 12 months; at 1 year; longer than 1 year ago; or don’t know) the majority of both groups had seen a dentist within the last year, with 99% (111/112) of controls attending a dentist within the last year compared with 86% (126/146) of subjects. Sixty-five percent (95/146) of children within the subject group and 84% (94/112) of children within the control group had attended a dentist within the previous six months. For the responses to this particular question, using the chi-squared statistic there was a significant difference (Chi-squared = 17.192, d f= 4, p = 0.001) for the responses between the subjects and controls. When asked what dental treatment their child received during the last visit to their dentist, the commonest response for both groups was a ‘check-up’ however, more ‘fillings’ and ‘extractions’ were provided for the
subject group than for the control group (Table 5).

In both groups, 97% of parents reported that their children used toothpaste when brushing and just over 80% of children brushed twice per day.

The majority of respondents were found to use a fluoride toothpaste, 88% of subjects (137/156) and 93% of controls (109/117) with no statistically significant differences between the groups.

**Discussion**

Subject bias may have been introduced due to the respondents completing the questionnaire (particularly the attitudinal types of questions) directly following reading the patient information leaflets and providing consent. This may have led to dental health issues being relatively prominent in the minds of both the subjects and controls.

The perception of health and medical conditions appeared similar in both groups. A serious condition such as leukaemia was ranked as more serious than influenza, dental decay and a fractured arm. Interestingly, dental decay was ranked as more serious than a fractured arm, even for those with JIA. However, although dental decay was thought by both groups to be a relatively serious condition, having a tooth extracted was not thought to be serious, even within the subject group with JIA. The disease itself appeared to be perceived more seriously than an end-stage sequel to dental caries. It may have been useful to investigate the opinion of primary tooth extraction versus permanent tooth extraction in order to gain insight into whether permanent teeth are thought to be more important than those of the primary dentition. Interestingly, data from the oral examinations showed patients with JIA experienced a higher prevalence of dental extractions and had fewer restorations placed compared with healthy controls [Welbury et al., 2003].

Contrary to the findings of a previous study by Saunders and Roberts [1997], when investigating respondents’ knowledge of dental disease and its prevention, in our study there appeared a similar level of knowledge between subjects and controls. The majority knew that dental decay could be stopped and that having sweet snacks caused harm to the teeth. Despite this knowledge, the previous work has shown an increased level of dental caries and poor oral hygiene in JIA patients throughout all age groups, with a statistically significant increase in dental caries in patients aged between 0 and 11 years [Welbury et al., 2003].

In Table 3 the majority of respondents in both groups felt that brushing teeth after eating sweet things would reduce decay. However, there was a significant difference seen (p = 0.054) between the responses by subjects and controls to ‘eating sweet things only at mealtimes can help reduce decay’. More subjects disagreed with this statement than controls. This infers that although both groups have a good grasp of the basic principles of preventing decay, the control group of healthy routine dental patients (seen at the dental hospital) have a better awareness of the importance of timing of sugary intakes.
Despite this apparent lower level of knowledge concerning dietary sugars control seen within the subject group, the majority of respondents from both groups agreed that avoiding sugar intake altogether was an effective way of stopping decay. An explanation for the greater awareness shown by the control group is that these patients have been seen within a specialist hospital setting and may have already received dietary counselling. However, perhaps patients with JIA (and their carers) should be made more aware of the ‘safer’ times to consume non-milk extrinsic sugars to enable a more consistent and achievable dietary change. The apparent lack of knowledge as to the ‘safer’ times to eat sugary foods may partially explain the higher levels of oral disease seen in JIA patients compared with controls [Welbury et al., 2003].

Attitudes towards prevention of dental disease were explored using questions involving tooth brushing, diet, fluoride, and fissure sealants. When the question of whether children should be given fluoride tablets was asked, the majority of subjects and controls ‘did not know’ (63% and 56% respectively). This demonstrates that parents and subjects in both groups were unaware of the efficacy of systemic fluoride supplements. Very few agreed that fluoride should be administered to children. The differences between the groups (Table 4) using the chi-squared statistic are significantly different (Chi-squared = 6.379, df = 2, p = 0.039).

This study was conducted in the northeast of England, where some water supplies are naturally or artificially fluoridated (Hartlepool and Newcastle respectively) and some water supplies contain very low levels of fluoride (parts of Northumberland and Durham). Therefore, parents from different geographical locations may have received different advice regarding systemic fluoride supplements, based upon their own water supply and this may be reflected partly in the results. However, the vast majority of respondents to the question were unsure, reflecting a poor awareness and understanding of the benefits of systemic fluoride. This is probably more indicative of having received no advice from a dental professional regarding fluoride supplementation. This should be cause for concern, particularly for those children with ‘special dental needs’ where studies have shown a higher prevalence of dental caries throughout different age groups [Welbury et al., 2003].

The majority of parents said that they controlled the amount of sugar that their child ate, but the extent of the control was not fully investigated and may vary greatly. For example, all parents gave their children sweets, however a quarter of parents of JIA children gave the child sweets on a daily basis – this was slightly less in the control group (20%). A dietary-based study has shown that patients with JIA may well be at a higher risk of developing dental caries because they tend to have smaller more frequent food intakes, possibly therefore increasing the frequency of intake of non-milk extrinsic sugars [Moynihan et al., 1999]. Moreover, it is a commonly held view in paediatric dentistry that children with underlying medical conditions may consume greater amounts of confectionery than healthy children [Tanchyk, 1991], thus causing a higher prevalence of dental caries in groups of children who are more vulnerable to the risks of morbidity posed by dental caries and its sequelae.

The dental health practices of attending a dentist and brushing regularly with fluoride toothpaste appeared to be important to the respondents of the questionnaire. The vast majority reported they had visited a dentist within the previous year. However for children, a shorter review period is advised [Crawford, 1998] and most specialist paediatric dentists adopt a pragmatic approach to the time interval based upon factors such as caries risk status and medical health.

A smaller proportion of children in the subject group (86%) had seen a dentist within the last 12 months compared with those children within the control group (99%). This difference was statistically significant using chi-squared analysis, (chi-squared = 17.192, df = 4, p=0.001). Chronic illness often has an impact upon dental attendance due to the extra burden of attending hospital/medical appointments and the results found in this study may be indicative of this. Treatment provision may also be impacted upon, for example an extraction rather than a restoration may be thought by some practitioners to be more appropriate in those patients with a less regular attendance pattern. It is noteworthy that when the type of treatment received was investigated (Table 5) more children from the subject group had a tooth extracted or filled during the last visit to their dentist. This appears to underline the findings of an earlier study showing patients with JIA experienced a higher prevalence of tooth extraction than their controls [Welbury, 2003].

Despite this, both groups seemingly were receiving regular dental care - the vast majority of subjects had seen a dentist within the previous 12 months.

Our findings contrast with those of an earlier study using the same questionnaire, where from a cohort of 60 children (aged between 2 and 16 years) with a congenital heart defect, 18% had never seen a dentist [Saunders and Roberts, 1997].
Conclusion
Overall the results found that the perception of health and illness demonstrated by both subjects and controls was based upon an appropriate hierarchy of relative severity.

The questions aimed at investigating dental knowledge revealed an understanding of the basic messages of prevention of dental disease involving all four pillars of prevention, but finer detail, for example the safest time to eat sweet food and the benefits of systemic fluoride supplementation appeared less well understood.

Respondents’ attitudes towards dental health and its prevention were favourable showing an awareness of the importance of good dental health habits. For dental health practices, the benefits of brushing with fluoride toothpaste were well known, and the majority within the study undertook this on a daily basis. The majority of respondents appeared to receive regular dental care. These findings should be considered in the context of multidisciplinary JIA clinics occurring without a dental professional as part of the team. The dental attitudes, knowledge and dental health practices of many JIA patients could be improved further by providing dental input, by for example dental hygienists within multidisciplinary JIA clinics.

References