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## Experience of illness uncertainty in parents of children with juvenile idiopathic arthritis

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### **Background**

An inevitable aspect of living with a chronic illness is dealing with illness uncertainty. Uncertainty has been described as a cognitive stressor which impedes coping ability and it has been found to be related to poorer wellbeing in both patients and carers in a range of long-term conditions. Given the unpredictable nature of juvenile idiopathic arthritis (JIA), the potential impact of uncertainty on parental well-being merits examination.

The aim of this study was to help gain a better understanding of illness uncertainty in parents of children with JIA.

### **Methods**

Design: Semi-structured interviews.

Participants: Parents of children and young persons (aged  $\leq 18$  years) with JIA; able to speak English.

Procedures: Participants were recruited through the National Rheumatoid Arthritis Society, JIA group. NRAS disseminated study information via email, newsletter, website and Twitter. Parents who were interested in taking part contacted the research team. The interviews, which were conducted by telephone, asked about the parent perspective on several aspects of their child's JIA, including symptoms, prognosis, treatment and impact of the illness. Thematic analysis was used to identify conceptual domains of illness uncertainty.

Approval was obtained from City, University of London School of Health Sciences Research Ethics Committee, reference Staff/16-17/08.

### **Results**

Twenty parents participated in the study, 19 mothers and one father. Their children with JIA had a mean (S.D.) age of 7.95 (3.9) years. Most children were female ( $n = 15$ , 75%), and had polyarthritis ( $n=12$ , 60%), oligoarthritis ( $n= 7$ , 35%) or systemic JIA ( $n=1$ , 5%).

Five domains of uncertainty were identified:

*Diagnosis, symptoms and prognosis* – this included feelings of uncertainty about the cause of their child's illness, accuracy of the diagnosis, interpreting their child's symptoms and disease prognosis.

*Medical management* – all parents expressed uncertainty regarding their child's medication, including concerns about its necessity, side effects and long-term impact and the consequences of changes to or stopping medication. There was also uncertainty when navigating health services.

*Impact of JIA* – uncertainty about the impact of JIA on their child's future emotional and social wellbeing, their ability to plan for events and the impact on the family.

*Parenting uncertainty* – parents reported uncertainty about how best to manage their child’s JIA, concerns about making decisions regarding their child’s care, and their own coping abilities. They were also unsure about aspects of their role as a parent and carer.

*Social awareness of JIA* – The uncertainty parents felt was set within a broader context of lack of understanding of JIA among family, friends and school.

### **Conclusion**

Parents expressed many concerns relating to their experience of uncertainty about their child’s JIA. Uncertainty related not only to disease and treatment outcomes but also to broader issues, which has implications for how to provide appropriate support to parents.