

# Parent and children's beliefs about childhood onset scleroderma

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## BACKGROUND

• Childhood scleroderma represents a rare and poorly understood spectrum of conditions and can be either localised or systemic.



Figure 1. Manifestations of childhood scleroderma. Left: Morphoea to trunk and back. Right: Contractures and limb length inequality caused by linear scleroderma.

• The beliefs that patients hold about their medical condition are important in adjustment and influence psychological outcomes such as distress, coping and functional disability.

• Previous studies in adults with scleroderma illustrated that illness beliefs are an important factor in patients' emotional responses.<sup>1</sup>

• No previous studies of illness perceptions in childhood scleroderma identified.

## AIMS

• This was a cross-sectional study that aimed to describe children's and parent's beliefs about scleroderma and their association with clinical parameters.

## METHOD

• Children with either localised scleroderma or systemic sclerosis (SSc) attending paediatric rheumatology clinics invited to participate at 4 UK hospitals: Alder Hey Children's Hospital, Liverpool; Royal Victoria Infirmary, Newcastle; Booth Hall Children's Hospital, Manchester; Royal National Hospital for Rheumatic Diseases, Bath.

• Children aged ≥ 11 years of age completed the Illness Perceptions Questionnaire –Revised (IPQ-R).<sup>2</sup> Example IPQ-R questions are shown in Table 1.

• For children aged < 11 years of age, the IPQ-R was completed by their parents or guardians.

• Clinical and demographic data were provided by consultant paediatric rheumatologists using modified Paediatric Rheumatology European Society (PRES) forms.

## INSTRUMENTS

• The IPQ-R contains a total of 70 questions grouped into 8 components or themes (shown in Table 1) that together make up patients' perceptions of their disease, in addition to perceived causes.

Table 1. Components and example questions of the Illness Perceptions Questionnaire - Revised.

Component	Example question
Illness Identity (symptoms)	Asks about the presence or absence of symptoms e.g. nausea, joint pain.
Timeline	'My illness will last for a long time'
Consequences	'My illness is a serious condition'
Personal control	'There is a lot which I can do to control my symptoms'
Treatment control	'My treatment can control my illness'
Illness coherence	'I don't understand my illness'
Timeline cyclical	'The symptoms of my illness change from day to day'
Emotional representations	'My illness makes me feel angry'

## RESULTS

• 28 children participated, together with their parents/guardians. Table 1 shows the demographic profile for the sample.

• The IPQ-R was completed by 17 children and 11 parents on behalf of children.

Table 2. Demographic profile of sample.

	Total sample n = 28	Localised scleroderma n = 24	SSc n = 4
Female, n(%)	19 (68)	15 (63)	4 (100)
White Caucasian, n(%)	24 (85)	20 (87)	4 (100)
Age at assessment, median (range) years	12.5 (5-17)	12.5 (5-17)	11.7 (7-14)
Disease duration, median (range) months	30 (2-135)	22 (2-35)	68 (15-83)

• Beliefs about the symptoms associated with scleroderma and the perceived causes are shown in Figures 3 and 4.

Figure 3. Beliefs about the symptoms associated with scleroderma (participants could select more than 1).

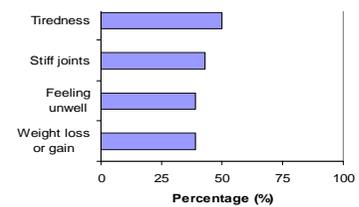
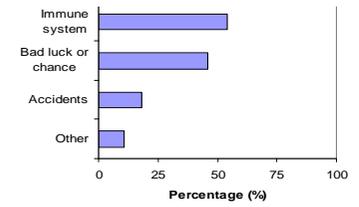


Figure 4. Beliefs about the causes of scleroderma (participants could select more than 1).



• No significant differences detected between parent and child scores in any of the 8 components (shown in Table 1) with the exception of beliefs about control, with children scoring more highly than parents (z=-2.40, p=0.015).

• There was a positive relationship between age and belief in personal control (ρ=0.53, p<0.01).

## CONCLUSIONS

• This study is the first to investigate the common-sense model of scleroderma held by children and their parents.

• Stronger beliefs in personal control held by children is an interesting initial finding, although this could be influenced by older children completing their own questionnaires.

• Perceptions of control are important in the adjustment to and management of chronic conditions, both for children and parents.

• Strategies to eliminate this mismatch may be important in facilitating parental adaptation to their child's illness.

## REFERENCES

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