The Roller Coaster of Juvenile Idiopathic Arthritis: A Qualitative Examination of Parents’ Emotional Responses to the Disease and Its Management

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**ABSTRACT**

**Parent Quotes:**

“It’s just tough for these kids. You know, it’s like he says li[ke], “Why me?” you know? (inhales, recomposes voice) – it’s interesting – it’s made him a stronger person. [cross talk] He’s really taking responsibility for his own health. [brief pause] He’s really growing up fast.” (experienced father)

“[novice English-speaking father] You can digest it, you research it, you read about it. You have to get used to it.”

**RESULTS**

**BACKGROUND**

Emotions are mixtures of primary emotions, just as some colors are primary and others made by mixing the primary colors.

R Plutchik. American Scientist 2001

**METHODS**

- **Study population:** Parents of youth with JIA. Three distinct groups were randomly recruited from the Rheumatology Clinics at BC Children’s Hospital and The Children’s Hospital of Eastern Ontario (CHEO):
  - 9 experienced English-speaking parents (duration of JIA > 6 months)
  - 5 experienced French-speaking parents (duration of JIA > 6 months)
  - 8 novice English speaking parents (duration of JIA 2-6 months)

- **Data collection:** Parents of youth with JIA took part in **focus groups** and **reciprocal interviews**, in which they spoke about their emotional experiences and how they relate to different phases of the disease manifestation, treatments, and interactions with peers and healthcare providers.

- **Analysis:** Review of transcripts of focus group discussions and reciprocal interviews was conducted.

- **Review of audio recordings** of focus group discussions and reciprocal interviews to enrich transcripts (based on pauses, noises, and other non-verbal cues).

- **Coding** of emotional experiences by two investigators using a list of 69 emotion labels plus **coding verification** by two other investigators.

**RESULTS CONT’D.**

**RESULTS**

- **Their children were** 2 to 16 years of age and had a variety of JIA subtypes and disease severity.
- **In the experienced group,** disease duration ranged from 9 months to 14 years.
- **In the novice group,** disease duration ranged from 2-6 months.

**METHODS**

- **Between onset and diagnosis:**
  - Mounting anxiety and confusion
  - Frustration with healthcare providers before a firm diagnosis was reached

- **Shortly after diagnosis:**
  - Shock, disbelief, and fear
  - Denial used as a coping mechanism
  - Overwhelmed by information

- **Throughout the disease parents felt** powerlessness and that the disease was a “time-consuming roller coaster”.

- **The type of arthritis did not affect** the range of emotions, but influenced the proportion of time in quiescence or ongoing symptoms, and the intensity of treatments and side-effects.

- **Between onset and diagnosis:**
  - Mounting anxiety and confusion
  - Frustration with healthcare providers before a firm diagnosis was reached

**CONCLUSION**

- **The emotional experiences of parents of children with JIA can be conceptualized,** as a parent put it, as roller coaster rides made of intensely emotional ups and downs.
- **This is similar to the emotional turmoil faced by parents of children with other chronic illnesses.**
- **Healthcare professionals caring for children with JIA need** to be deeply aware of this.
- **Care provision should include resources** to make the ride more bearable.