

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

Background/Purpose: During a recent study we conducted to identify parents, parents and clinicians' priorities in describing the course of juvenile idiopathic arthritis (JIA), parents expressed intense emotions related to the disease and its management even a decade after their children's diagnosis. Here we describe the predominant emotional experiences reported by parents and how they relate to different phases of the disease manifestation, treatments, and interactions with peers and healthcare providers.

Methods: We analyzed focus group transcripts and reciprocal interview analyses involving 9 experienced English-speaking parents, 5 experienced French-speaking parents and 8 novice parents (between 2 and 6 months since diagnosis). Their children were 2 to 16 years of age and had a variety of JIA subtypes and disease severity. Qualitative analysis included review of audio recordings 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, coding verification by two other investigators, and analytical discussion and synthesis by our interdisciplinary team (to agree on what emotions were predominant at different stages of the disease, who or what were those emotions directed at, and how disease characteristics or parent background shaped them).

Results: The time between onset and diagnosis was described by parents as a period of mounting anxiety, confusion and frustration with healthcare providers before a firm diagnosis was reached. The time shortly after diagnosis was described as a time of shock, disbelief, and fear during which parents often used denial as a coping mechanism, combined with feeling overwhelmed by a deluge of information about the disease. Later in the disease course, at times of disease quiescence the predominant emotions were annoyance and worry about treatment side effects, and the fear of unpredictable flares. At times of increasing or ongoing symptoms the predominant emotions were admiration for the way their children coped with the disease, and frustration with peers and teachers that could not adequately justify the changes in the child's willingness to engage in physical activity and school work. This was also a time of frustration with increasing treatment and side effects. Throughout the disease parents felt a sense of powerlessness and that the disease was a "time-consuming roller coaster". The subtype of arthritis did not affect the range of emotions experienced, but influenced the proportion of time in quiescence or ongoing symptoms, and the intensity of treatments and side-effects.

Conclusion: The emotional experiences of parents of children with JIA can be conceptualized, as a parent put it, as roller coaster ride made of intensely emotional ups and downs. This is similar to the emotional turmoil faced by parents of children with other chronic illnesses, but JIA usually does not conform them with the chronic, grief produced by progressive degenerative illnesses or the threat of imminent death.

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

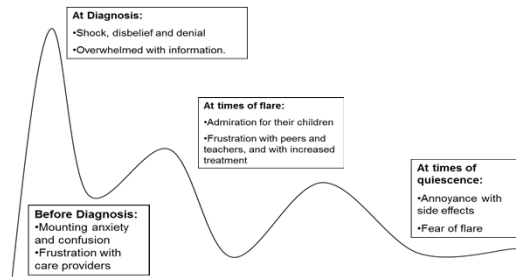
METHODS

- **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.
- Discussion and synthesis by interdisciplinary team.

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.

Figure 1:



- Throughout the disease parents felt powerless 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
- Shortly after diagnosis:
 - Shock, disbelief, and fear
 - Denial used as a coping mechanism
 - Overwhelmed by information

RESULTS CONT'D.

Parent Quotes:

"It's just tough for these kids. You know, it's like he says like, "Why me?" you know? (continues crying) So it's just... (gasps) Ah! It is what it is, but you know in some ways (inhales, recomposes voice) – it's interesting – it's made him a stronger person. [Cross talk] He's really taking responsibility for his own health. And you know it's early for a kid to do that. Like he's growing up fast." (novice father)

Just [brief pause] shocked I guess when I heard that she had arthritis, simply because I'd never heard of a child with arthritis before. But... And then coming here and realizing that it's more common than people are... or than it's known to be to people, I guess. And yeah, I tried doing research on the internet, but I found that was just kind of useless because it generally is inaccurate. [pause] And that's it. (Novice English-speaking father)

"No, no signs, no instances. It's funny, I'm getting emotional, the first time talking about it. (voice breaks, short pause) So we didn't have... We didn't actually get any documentation or introduction to the fact that it might be juvenile arthritis. We thought it was an injury. So we had done... peripheral research, (voice breaks) but didn't really know... Sorry, I need to back away for a second." (experienced father)

"You can digest it, you research it, you read about it. You have all the information, but it's still a roller coaster ride for like eight years now, so..." (experienced mother)

"Oh my God, what's going to happen to our life now? This is crazy. Everything just sort of falls apart and you focus on that child, because they're really sick and it's scary." (experienced mother)

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.