Growing Up with Juvenile Idiopathic Arthritis: School and Social Life in the Time of Social Media

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Abstract

Background

Juvenile idiopathic arthritis is a chronic inflammatory condition interfering with daily activities, social integration and scholar attendance in children because of pain and joint inflammation during disease flares. Online resources might help children with JIA improve their social interactions and enhance their knowledge about their disease and the available therapeutic strategies.

This study aims to reveal the social issues encountered by teenagers prone to JIA and determine their perception about the impact of social media on their daily life.

Methods:

We conducted phone interviews with children suffering from JIA, aged between 8-16 years old.

Results:

Individual interviews were held with 22 adolescents diagnosed with JIA. Fifty-two percent felt like outcasts and rejected by their peers because of their illness. Most of the participants expressed a need for their friends to be informed about their JIA diagnosis. Twenty-two-point seven percent stated playing sports for more than 5 hours a week. 31.8% found their physical performance not affected by their disease. Ninety-seven of the participants confirmed that they're using social media on average 3 hours a day. YouTube and Facebook were ranked respectively as the first and the second preferred platforms. Seventeen percent of children viewed these platforms as positive and helpful in dealing with JIA, especially by taking their mind off of the pain, dealing with the stress resulting from the lack of mobility, and facilitating interactions with others.

Conclusion:

Social integration in children with JIA is still challenging. Social media is a helpful tool to relieve pain and improve children's social interactions.

Background

Juvenile idiopathic arthritis (JIA) is the most common chronic rheumatic disease in childhood [1]. It encompasses all forms of arthritis that begin before the age of 16 years, persist for more than 6 weeks, and are of unknown etiology. Recurring arthritis is the hallmark of this disease, characterized by pain and loss of function and is frequently accompanied by loss of energy [2]. Even in the era of modern treatment with improved outcome on biologic therapies, many children with JIA still experience flares and difficulties to attend daily life activities [3]. JIA related symptoms have been associated with interference in the daily life of children and adolescents including their friendships, school attendance and even their family life. However, not many studies have investigated the interference of JIA in the daily life of

children. This day to day life is undeniably affected by the great accessibility to internet and the progression of social media [4]. The purpose of our study was to determine the point of view of children with JIA regarding the impact of social media on their lives. The aim of this qualitative study was to elicit the experiences of children with JIA during school and family life and their perspectives and expectations regarding online resources and social media.

Methods

Procedure

Participants were recruited from the rheumatology department of Kassab institute.

In all cases, parents of interested children and adolescents were informed about the purpose of the study and they consented to participation. Inclusion and exclusion criteria were also checked. Their privacy and confidentiality were guaranteed. Taking into account that participants were from all over the country, phone calls were used for the interviews. All interviews were conducted by a rheumatologist and all data were collected from the clinical files of the patients.

Participants

Inclusion criteria were: age from 8 to 16 years old, diagnosis of JIA was based on the International League of Associations for Rheumatology criteria (ILAR). Those with a severe mental illness, cognitive problems were excluded.

According to previous studies we estimated that a sample of 22 adolescents was optimal to conduct the interviews [5–7]. A list was derived from the outpatient clinic agenda and eligible patients were contacted by phone by our team. No refusals were noted. In order to be eligible to participate in this study, a subject had to meet the following criteria: 1. Diagnosed with JIA according to the ILAR categories at least 6 months prior to the start of the study; 2. Between 8 and 16 years of age; 4. Informed consent by patient and parents as well.

Data collection

Gender, age, age at diagnosis, JIA subtype and the current level of education were noted and collected from the patient record. A list of topics was designed. The interview was open to including remarks and suggestions emerging from participants.

The interviewer was nondirective, allowing participants to freely express their opinions about the general topics in a dialogue. Interviews lasted from 15 to 35 min.

The three main themes were the following:

1. Social life: Friendships and family life

2. School and physical activity
3. Online resources

The subjects and questions are summarized in **Table 1**.

Table 1
Agenda for the semi-structured interviews

1- Social life: Friendships and family life
Did the disease impact your friendships: alienating/Getting closer to friends
Do you feel different from your friends? How?
Do you feel your friends/family understand your disease?
Do you feel supported and understood by friends/members of your family?
Do you feel treated the same as your siblings? If not, how?
2- School and physical activity
How does/did the disease influence your time at school?
Are/were there adjustments made to support you?
Did you fail at school at one point? If yes, was it related to your disease?
Do you participate in high level physical activities?
Did the disease influence your physical activity performance and time?
Do you play sports more than 3 hours/week?
Do you play sports in school? Is it different from your friends/affected by JIA?
Did your doctor prevent/encourage you some sports?
3- Online resources
Are you active en social media?
Which platform?
How much time/day?
What are you looking for mainly?
Do you find social media useful/helpful in relationship to JIA?

Analysis

Themes were derived from the data and organized in the three topics: Social life: Friendships and family life/ School and sports/Online resources. Analysis started after the first interview and continued throughout the study.

Results

Sample characteristics

A total of 22 patients were included in this study, 7 males and 15 females with a median age of 14 years (range 8–16). The individual patient characteristics are shown in Table 2.

Table 2		
Sociodemographic characteristics of JIA patients		
Age (years)	14 (8–16)	
Disease duration (SD; range)	8 years (1–11),	
Sex ratio	0.46	
Actual Pain intensity Median (years)	20 (10-40)	
JIA subtype (n)	ERA	11
	Oligo articular	7
	Poly articular RF -	2
	Poly articular RF +	1
	Systemic JIA	1
JIA: <i>juvenile idiopathic arthritis</i> ERA: <i>Enthesitis</i> -related arthritis		

Content analysis from the interviews

Social life: Friendships and family life

Seventy eight percent felt understood and supported by their family in dealing with the different aspects of JIA. Twenty-six per cent felt more spoiled than their other siblings, creating tension sometimes. Fifty two percent felt different and not accepted by their peers because of the JIA. Some children made comments about feeling different from others because of JIA and feeling criticized by peers, including comments referring to criticism they have received as a consequence of JIA.

There were also comments about not feeling believed and not feeling understood with regard to invisible symptoms such as pain or other symptoms.

Coping strategies were ignoring negative comments, maintaining activities with friends, despite feeling bad. When asked what they need to better manage their friendships, most of the participant expressed a need for their friends to be informed about the JIA diagnosis, its characteristics, course, impact, and consequences.

School and physical activity:

Eight percent of the children were in elementary school, and 21.7% in high school. Eighty seven per cent reported school absenteeism due to JIA (pain, being hospitalized) with a mean of 8 missed school days. Forty-three per cent failed in their schooling at some point. Thirty percent thought it was related to the consequences of their disease. Only 47.8% found the school staff to be helpful and supportive.

Only one (4.5%) participant was engaging in high level sports. 22.7% stated playing sports for more than 5 hours a week. Forty-five percent did engage in sport activity at school. Among which 27% engaged in all types of sports. 31.8% found their performance not affected by their disease. Some of the participant found their performance limited because of pain (18%), coxitis (9%), and functional limitations (18%). One patient had a heart condition limiting his physical activity as well. 45.5% found their symptoms worsen by playing sports, versus 9.1% who found it got better. Only 27.3% stated having medical counseling from their doctor regarding physical activity.

Online resources and social media

Ninety-seven of our participants confirmed that they're using social media, for a mean of 3 hours per day. YouTube and Facebook came back as the first two preferred platforms: 82.6% and 69.6% respectively, followed by Instagram 30.4%, Tiktok 21.7, Snapchat 17.4% and WhatsApp 8.7%. Seventeen percent of children viewed these platforms as a positive and helpful in dealing with JIA, specially taking their mind of pain, dealing with the stress resulting from the lack of mobility and facilitating interactions with others. All of our participants were in favor of obtaining information about JIA, and interacting with others, including people with experience with the JIA (peers or health professionals) through an online resource. Interestingly, none of the participants considered online resources as a place to interact with health professionals or have access to information about JIA.

Discussion

In this study we researched experiences of adolescents with JIA in relation to their families, during school life and physical activities, as well as their perspectives and expectations regarding social media and online resources. Individual interviews were held with 22 adolescents diagnosed with JIA with different social, economic and educational backgrounds. The experiences of having JIA in families and at school show varying degrees of understanding and support as well as differences in adjustments that were provided. However, and as we expected, the most talked about physical activities' limitation was pain. Pain interference in social activities involving physical activities has been described in the literature in several studies [8, 9]. Regular physical activities have an impact on muscular strength, physical and

cardiovascular capacity, as well as psychosocial health [10]. Descriptive observational studies support the importance to carry out sports safely, without risk of exacerbations. It is useful to combine a training program characterized by balance exercises, stretching, and strengthening [11, 12]

It is important in exercise therapy, and especially in the pediatric age group, to determine specific and individualized interventions [13].

Children also expressed their feelings of being different, their fears of being criticized by peers, or not believed. These feelings have been mentioned along the studies reviewed [14–16]. Some studies showed how children can be victims to bullying because of their disease [14]. Adolescents also expressed their need for information on how to manage their life, when and how to talk about JIA or social support, aligning with some former studies on this matter [6, 16].

A Nordic study conducted in 2019 assessed school attendance and participation in physical education in a prospective multi-center JIA cohort. School attendance increased during the disease course, and was generally high in children 8 years after disease onset in the Nordic JIA cohort [11]. Our results indicate increased school absence in children with JIA. JIA may have a higher impact on participation in less privileged countries, due to limited access to expensive medical treatment [17]

Adolescents are also heavy users of the Internet, preferably use their Smartphone, and mainly to speak with friends through social networks and search for information.

Unlike our study that showed a preference for YouTube and Facebook, other studies showed Instagram and WhatsApp to be the highest used of apps among adolescents [18, 19]. Although their potential has been suggested for health [19], they have rarely been used in this direction. A recent study reviewed the literature about these two tools and found that WhatsApp has mainly been used in clinical decision-making and patient healthcare, and Instagram has been used for informative or motivational purposes [20]. These two tools give us an extraordinary opportunity to facilitate the interaction requested by adolescents. On the light of our study, we suggest adding Facebook and YouTube as additional resources for accessible medical information and motivation.

The main limitation of this work is it's a small number of our population, due to the rarity of this disease in our country.

Conclusions

Family and friends are central figures in children and adolescents' life and can represent an important support system to manage pain. The results of our study may be important to help researchers and health professionals to advance in the design of an efficient supporting system relying on these parties. As the experiences of patients affected by JIA during their school life, may be comparable to the barriers they encounter in adult working life, having a strong supporting system from an early age is an essential step for JIA patients to become a healthy productive adult. Finally, Online resources especially now with

the emerging role of social media can be also helpful in managing JIA and improving social networks with friends, as well as getting helpful information.

Abbreviations

ILAR

International League of Associations for Rheumatology criteria

JIA

juvenile idiopathic arthritis

Declarations

Ethical Approval and Consent to participate: yes

- Consent for publication: NA

- Availability of supporting data: NA

- Competing interests: NA

- Funding: No

- Authors' contributions: SM and FH wrote the manuscript; WT and DBN edited the language; KM and DK corrected the scientific data, WH approved the final manuscript.

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