SNAPSJIA study Survey of Adolescents' Needs and Parents' Views on Sexual Health in Juvenile Idiopathic Arthritis

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Abstract

**Background:** Although the advent of new therapeutics for juvenile idiopathic arthritis (JIA) patients has considerably lessened the impact of the disease and reduced sequelae, the outcomes of JIA remain important in their lives and more specifically for sex life. According to the world health organization, sexual health (SH) is "a state of physical, emotional, mental and social well-being in relation to sexuality". The aim of the study was to determine the expectations of adolescents with JIA and the perceptions of their parents regarding knowledge and communication with healthcare providers (HCPs) in the field of SH.

**Methods:** From September 2021 to April 2022, a French survey with anonymous self-administered questionnaires, was conducted among JIA patients and their parents in nine rheumatology centers and three patient associations. On the advice of a psychiatrist, we interviewed adults (age 18–45 years) for necessary hindsight from the subject.

**Results:** 76 patient and 43 parent questionnaires were analyzed. Half the patients thought JIA impacted their love life, the results were less clear-cut for their sex life. 58.7% would be comfortable discussing the subject with HCPs, but only 26.3% had done so, mainly regarding biomedical issues. Patients and parents thought the topic should ideally be addressed in hospital in an individual patient education session (51.3%, 34.9% respectively), a regular consultation (47.4%, 53.5%) or a dedicated consultation requested by the adolescent without parents being informed (38.2%, 20.9%). Most thought HCPs should be proactive (77.6% of patients, 69.8% of parents). The use of digital resources was significantly more cited by patients than by parents: video information (29.0% vs. 9.3%, \( p = 0.0127 \)) smartphone application (25.0% vs. 9.3%, \( p = 0.0372 \)).

**Conclusion:** HCPs should address this unmet need for SH in hospital. The main difference between patients and parents was the use of digital tools, a preferred vector of communication for adolescents. Parents need to be reassured about their content.

**Clinical trial registration number:** NCT04791189

**BACKGROUND**

Juvenile idiopathic arthritis (JIA) is a group of inflammatory joint disorders appearing before age 16 years, lasting for more than 6 weeks, and with no recognized cause [1]. Its prevalence in Europe and North America ranges from 16 to 150/100,000. In France, 2,000 to 4,000 young people are thought to be affected [2].

Some patients recover spontaneously in childhood and adolescence, but it is estimated that more than 50% will have active disease in adulthood [3]. Although the advent of new therapeutics for JIA patients has considerably lessened the impact of the disease and reduced sequelae [4], the outcomes of JIA remain important in their lives [5–7] and for sex life in particular [8–10]. Moreover, for diseases whose symptoms are not necessarily visible, such as JIA, it has been shown that the repercussions and suffering felt by patients are worsened by their desire to conceal their condition [8]. Patient management is based on a multidisciplinary care relationship in pediatrics involving three key actors: patients, parents, and healthcare providers (HCPs). In this context, sexuality is especially hard to discuss [11].

The World Health Organization (WHO) defines sexual health (SH) as "a state of physical, mental and social well-being in relation to sexuality"[12]. Regarding the SH of patients with chronic diseases, it is usual to distinguish three levels of impact: primary (impact of the disease and treatments on sexual response) [13–16], secondary (symptom impact) [10, 17–19], and tertiary (psychosocial impact) [20, 21].

Studies on the impact of JIA on SH are scant [8–10]. An international study has drawn up a checklist of topics to be addressed by age group, as specified by HCPs [22]. There is interest in the SH topic, but the specific needs of patients and parents have not yet been identified.

In France, the national SH strategy sets out proposals for action spanning the period 2017–2030[23]. This strategy is in line with a comprehensive approach to improving sexual and reproductive health. More specifically for JIA patients, actions include "investing in SH promotion, especially for young people, addressing the sexuality of people with chronic disease, and promoting research". However, it has been shown that sex education for adolescents and more broadly for all young people in schools remains insufficient [23].

Our objective was to determine the expectations of adolescents with JIA and the perceptions of their parents regarding knowledge and communication with HCPs in the field of SH.

**METHODS**

**Study design and participants**

A French multicenter survey was conducted from 24 September 2021 to 8 April 2022 among patients diagnosed with JIA (according to the International League of Associations for Rheumatology classification [24]), aged 18–45 years and their parents, in nine rheumatology centers. To optimize the recruitment, three patient and parent associations were also approached: "Association France Spondyloarthrites" (AFS, patients with
spondylarthritis), "Association Nationale de Défense contre L'Arthrite Rhumatoïde" (ANDAR, patients with rheumatoid arthritis) and KOURIR (parents of children and adolescents with JIA). Participants completed anonymous questionnaires on SH during the adolescence of patients.

On the advice of two child psychologists and a psychiatrist, we chose to interview an adult population (age 18–45 years) rather than adolescents to obtain strong data from their recollections of adolescence with necessary insight from the subject.

The project was approved by a French regional ethics committee ("Comité de Protection des Personnes" d'Ile-de-France IV, No. 2020-A01004-35) and was conducted in accordance with the Declaration of Helsinki.

In the rheumatology centers, two hundred paper surveys were sent. The process began with information via a rheumatologist for all JIA patients, inviting them to take part in the study. Each JIA patient could ask their parents to take part in the study. Inclusion of JIA patients did not require participation of their parents in the survey or vice versa. All those who consented to take part (patients with JIA and their parents) were given two options to complete the anonymous questionnaire: (i) a paper version or (ii) an online version using the REDCap electronic data capture tool [25]. A questionnaire to explore refusals to take part was systematically offered.

In the case of the online survey form, the consent statement was included at the beginning of the questionnaire.

For the associations, an invitation to take part in the study with the link to the online questionnaire and the information leaflet was distributed by the association's newsletter, and on the association's website.

Prior to designing the questionnaires (one for patients and one for parents), an extensive literature review was made. In this light, a panel of experts composed of two sexologists, two rheumatologists, a pediatrician, a therapeutic education nurse sexologist, two biostatisticians, a child psychologist, and the director of a patient association, developed the pre-final version of the questionnaires. Two patients with JIA and two parents reviewed the pre-final versions for content validity (removal of redundancies, correction of ambiguous questions, and rephrasing items for more clarity). The questionnaires were then tested on a sample of nine patients and six parents to assess their acceptability.

Participants could also make additional comments. The final versions of the questionnaires are presented in English as supplementary materials, additional file 1 (for patients) and additional file 2 (for parents).

Statistical analysis

A descriptive analysis of the patient and parent responses was carried out. Categorical variables are presented as numbers and percentages, continuous variables as means and standard deviation (SD).

Responses to open-ended questions were analyzed by AC, a team member with experience in qualitative analysis, and CSa, a therapeutic education nurse sexologist involved in the study design, and classified by verbatim reports, without pre-determined themes.

The responses of patients and parents were compared using chi-squared tests (or Fisher’s exact tests as appropriate).

All statistical analyses were performed using SAS® Version 9.4 (SAS Institute, Cary, NC, USA). All the tests were two-sided. Statistical significance was set at $p < 0.05$.

RESULTS

Demographics and clinical data

The responses of 76 patients and 43 parents were analyzed (Fig. 1).

Participants’ characteristics are reported in Table 1.
Table 1

<table>
<thead>
<tr>
<th>Characteristics of participants</th>
<th>Patients (N = 76)</th>
<th>Parents (N = 43)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years), mean (SD)</td>
<td>25.6 (7.2)</td>
<td>54.3 (5.6)</td>
</tr>
<tr>
<td>Female gender, n (%)</td>
<td>57 (75.0)</td>
<td>38 (88.4)</td>
</tr>
<tr>
<td>Family situation, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>27 (36.5)</td>
<td>2 (4.7)</td>
</tr>
<tr>
<td>With a partner</td>
<td>46 (62.2)</td>
<td>32 (74.4)</td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>1 (1.4)</td>
<td>9 (20.9)</td>
</tr>
<tr>
<td>Educational level, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary and secondary school</td>
<td>8 (10.8)</td>
<td>19 (44.2)</td>
</tr>
<tr>
<td>Higher education level</td>
<td>66 (89.2)</td>
<td>24 (55.8)</td>
</tr>
<tr>
<td>Number of other children in the family unit, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>4 (6.0)</td>
<td>7 (16.3)</td>
</tr>
<tr>
<td>1</td>
<td>27 (40.3)</td>
<td>17 (39.5)</td>
</tr>
<tr>
<td>2</td>
<td>25 (37.3)</td>
<td>16 (37.2)</td>
</tr>
<tr>
<td>≥ 3</td>
<td>11 (14.5)</td>
<td>3 (7.0)</td>
</tr>
<tr>
<td>Parents separated during the adolescence, n (%)</td>
<td>21 (30.4)</td>
<td>-</td>
</tr>
<tr>
<td>Age of adolescents at JIA onset (years), mean (SD)</td>
<td>7.8 (5.0)</td>
<td>7.2 (5.2)</td>
</tr>
<tr>
<td>Age of adolescents at JIA diagnosis (years), mean (SD)</td>
<td>8.9 (5.0)</td>
<td>8.4 (5.4)</td>
</tr>
<tr>
<td>Adolescents’ JIA subtype, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>oJIA</td>
<td>3 (4.0)</td>
<td>7 (16.3)</td>
</tr>
<tr>
<td>pJIA</td>
<td>32 (42.7)</td>
<td>13 (30.2)</td>
</tr>
<tr>
<td>ERA</td>
<td>13 (17.3)</td>
<td>5 (11.6)</td>
</tr>
<tr>
<td>sJIA</td>
<td>15 (20.0)</td>
<td>6 (14.0)</td>
</tr>
<tr>
<td>psoJIA</td>
<td>4 (5.3)</td>
<td>4 (9.3)</td>
</tr>
<tr>
<td>undJIA</td>
<td>6 (8.0)</td>
<td>3 (7.0)</td>
</tr>
<tr>
<td>unknown</td>
<td>2 (2.7)</td>
<td>5 (11.6)</td>
</tr>
<tr>
<td>Adolescents belonging to a patient association, n (%)</td>
<td>15 (19.7)</td>
<td>15 (35.7)</td>
</tr>
<tr>
<td>Adolescents in a support network, n (%)</td>
<td>8 (10.5)</td>
<td>13 (30.2)</td>
</tr>
</tbody>
</table>

Most of the JIA patients were women (75.0%), with a mean age of 25.6 years (SD 7.2), and with an educational level higher than high school (89.2%). The mean age at diagnosis was 8.9 years (SD 5.0). The mean JIA subtype was polyarticular (42.7%) with rheumatoid factor (71.9% of polyarticular subtype). The mean age of first sexual intercourse was 18.1 years (SD 3.7), 64.5% had received a mean of 4 hours of sex education in school.

Most of the participating parents were mothers (88.4%), with a mean age of 54.3 years (SD 5.6), and an educational level higher than high school (55.8%). They were mainly parents of daughters (81.4%) with a mean age of 24.2 years (SD 5.1). Here again, the diagnosis of JIA was pre-puberty (mean age 8.4 years, SD 5.4). The most common JIA subtype was polyarticular (30.2%) with rheumatoid factor (for 84.6% of polyarticular forms).

Impact of JIA on SH

Half of the patients thought their rheumatism had an impact on their love life, as did 51.2% of the parents. The main causes mentioned by patients were body shame (46.1% vs. 34.9% for parents, $p = 0.2357$), low self-esteem (39.5% vs. 20.9% for parents, $p = 0.0384$) and the fact that adolescents with JIA were more mature than their peers (31.6% vs. 18.6% for parents, $p = 0.1252$), shifting their inter-individual relationships.
For the patients, the impact of the disease on their sex life was not clearcut. For the 32.9% of the patients who noted an impact of JIA, the main difficulties reported were related to the disease activity: fatigue (70.6%) and pain (61.8%). For the parents, 23.3% thought that JIA had an impact on their child's sexuality, related to fatigue (50.0%) and pain (64.3%).

Love life was discussed with parents by 52.0% of the JIA patients, although 72.1% of the parents felt that they had exchanged views on this issue with their child, and when they had not, the reasons given were the very emotional content (41.7%) or lack of knowledge (16.7%).

For sex life, dialogue was reported for 19.7% of patients and 55.8% of parents.

For parents, the difficulties talking about sex life with their children were that it was emotionally (50.0%) or culturally complicated (11.1%), and sometimes that the child was closed to dialogue (“sometimes he agreed and sometimes he didn't want to talk about it”, “my child refused to talk about his intimacy”).

Of the patients, 58.7% reported that they would not be embarrassed to discuss the subject of SH with an HCP, although only 26.3% reported having done so. The reasons given for not addressing SH were embarrassment or shyness or lack of self-confidence (41.9%), the fact that it was an intimate subject (19.4%), the attitude or representations of the health professional (16.1%), the presence of parents (12.9%) and finally doubts about the relevance of the subject (12.9%).

For both patients and parents, when the subject of SH was discussed, it was mainly when the professional was proactive (respectively 55.6% vs. 42.1%) and with a hospital rheumatologist (50.0% vs. 68.4%). The main issues discussed were biomedical.

Their main sources of information were reference persons at school (46.1%) or in the family (43.4%), although social networks (Facebook, Twitter, Wikipedia, discussion forums) played a significant role (34.2%).

Parents declared that their child had talked with an HCP in 45.2% of cases, more than declared by the children themselves (26.3%, p = 0.0439). There were some significant differences between the patients’ and parents’ answers concerning the sources of information. While parents believed that adolescents interacted with HCPs (39.5% vs. 21.1% of patients, p = 0.0305), young people identified digital resources such as TV programs (21.1% of patients vs. 2.3% of parents, p = 0.005), radio (18.4% vs. 0%, p = 0.0027), films (18.4% vs. 4.7%, p = 0.0344) or magazines (15.8% vs. 2.3%, p = 0.0302) as a resource.

We note that 27.9% of parents cited no source of information about SH. When they did report some, the HCPs were the most often cited (30.2%). The great majority of parents thought there were few opportunities for dialogue in hospital (85.4%), as did the patients (92.0%). At the same time, 82.9% of the parents and 62.7% of the patients thought it was important to discuss SH during hospital follow-up.

**Patients’ and parents’ needs regarding SH**

Figure 2 presents the needs expressed in the context of optimal care provision.

Patients and parents preferred the topic to be addressed in hospital during an individual patient education session (51.3% and 34.9% respectively, p = 0.0837), a regular consultation (47.4% and 53.5%, p = 0.5212) or a consultation dedicated to this topic, at the adolescent’s request, without the parents being informed (38.2% and 20.9%, p = 0.0528).

Both patients and parents considered that the person most competent to discuss the subject in hospital was a gynecologist (68.4% vs. 55.8%, p = 0.1690), a rheumatologist (55.3% vs. 58.1%, p = 0.7612), a psychologist (52.6% vs. 34.9%, p = 0.0621) or a peer expert (46.1% vs. 25.6%, p = 0.0276) (Fig. 3).

The most approachable persons to discuss the subject in hospital were a gynecologist (47.4% vs. 44.2%, p = 0.7380), a rheumatologist (40.8% vs. 46.5%, p = 0.5446), a psychologist (39.5% vs. 32.6%, p = 0.4528) or a peer expert (38.2% vs. 37.2%, p = 0.9184) (Fig. 3).

For adolescents, in community medicine, a gynecologist (71.1% vs 48.8% of parents, p = 0.0159), a sexologist (59.2% vs. 13.9%, p < 0.0001) and a school nurse (42.1% vs. 16.28%, p = 0.0039), a family planning counselor (42.1% vs. 13.9%, p = 0.0016), and a psychologist (42.1% vs. 37.2%, p = 0.6010) were also considered the most competent.

Patients were more comfortable in community medicine with a gynecologist (50.0% vs. 44.2% of parents, p = 0.5419), a sexologist (40.8% vs. 14.0%, p = 0.0024), a family planning counselor (34.2% vs. 11.6% p = 0.0070) and a psychologist (31.6% vs. 32.6% p = 0.9124).

**Communication facilitators**

We asked about items that made it easier to discuss the subject. The results are reported in Table 2.
Table 2
Facilitating elements to discuss SH with HCPs according to juvenile idiopathic arthritis patients and parents.

<table>
<thead>
<tr>
<th>Facilitators of discussion of SH between adolescents and HCPs in hospital</th>
<th>Patients (N=76)</th>
<th>Parents (N=43)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>The HCP addressing the issue first</td>
<td>59 (77.6)</td>
<td>30 (69.8)</td>
<td>0.3426</td>
</tr>
<tr>
<td>Parents not present at the consultation</td>
<td>51 (67.1)</td>
<td>21 (48.8)</td>
<td>0.0502</td>
</tr>
<tr>
<td>The proper occasion</td>
<td>49 (64.5)</td>
<td>23 (53.5)</td>
<td>0.2389</td>
</tr>
<tr>
<td>An HCP who is comfortable with the subject</td>
<td>45 (59.2)</td>
<td>23 (53.5)</td>
<td>0.5446</td>
</tr>
<tr>
<td>Availability of a brochure on the subject</td>
<td>34 (44.7)</td>
<td>21 (48.8)</td>
<td>0.6665</td>
</tr>
<tr>
<td>Discussion of the topic with an HCP of the same gender</td>
<td>34 (44.7)</td>
<td>3 (7.0)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>That the HCP identifies the &quot;right&quot; time</td>
<td>24 (31.6)</td>
<td>18 (41.9)</td>
<td>0.2595</td>
</tr>
<tr>
<td>Informative video on the subject (viewable by the adolescent)</td>
<td>22 (28.9)</td>
<td>4 (9.3)</td>
<td>0.0127</td>
</tr>
<tr>
<td>A smartphone application (information, monitoring of the disease, etc.)</td>
<td>19 (25.0)</td>
<td>4 (9.3)</td>
<td>0.0372</td>
</tr>
<tr>
<td>Having time</td>
<td>18 (23.7)</td>
<td>7 (16.3)</td>
<td>0.3408</td>
</tr>
<tr>
<td>Being able to speak about it anonymously (via an internet connection)</td>
<td>16 (21.0)</td>
<td>3 (7.0)</td>
<td>0.0440</td>
</tr>
<tr>
<td>An informal exchange with another adolescent (while waiting for a consultation or in a hospital room, for example)</td>
<td>12 (15.8)</td>
<td>3 (7.0)</td>
<td>0.1641</td>
</tr>
</tbody>
</table>

HCP: healthcare provider; SH: sexual health.

Most patients and parents thought that HCPs should be proactive (77.6% of patients and 69.8% of parents).

The statistically significant differences were presence of parents during this consultation (67.1% of patients vs. 48.8% of parents, p = 0.0502) and the HCPs being of the same gender as the adolescent (44.7% of patients vs 7.0% of the parents, p < 0.0001). Also, the use of digital resources was significantly more often cited by patients than by parents: available video information (29.0% vs. 9.3%; p = 0.0127), smartphone applications (information, monitoring of the disease, etc.) (25.0% vs. 9.3%; p = 0.0372).

Finally, 79.0% of the patients wanted biomedical information, followed by discussion (68.4%), but parents less so (58.1%, p = 0.0158 for biomedical information and 39.5%, p = 0.0022 for discussion), reassurance (64.5% of patients vs. 60.5% of parents; p = 0.6634), and to be listened to (51.3% vs. 48.8%; p = 0.7950), while sexual treatment (27.6% vs. 14.0%; p = 0.0870) and being directed to SH competent professionals were less frequently mentioned (39.5% vs. 27.9%; p = 0.2047).

All the major SH themes interested all the respondents yet were rarely or never addressed.

DISCUSSION

To our knowledge, this is the first study that identifies the needs of adolescents with JIA in the field of SH and considers the point of view of their parents.

The results are evidence that our study is relevant, about half of both patients and parents reporting love life difficulties arising from JIA. These difficulties were linked to the disease activity, confirmed by a further study in rheumatology [26].

Love difficulties in adolescence are real, since sentimental attraction develops from a very young age. Impact on sex life was less clearcut. Almost one third of patients had difficulties such as fatigue and pain that decreased sexual desire, ascribed to JIA in almost two-thirds of cases. Concerning genital sexual activity, it was hard to distinguish between difficulties related to first experiences and the real impact of the disease on sexual response. This could explain why impact on sex life was finally felt to be moderate. The declared age of entry into genital sexuality in France is on average 17 years, according to a national survey on sexuality in the general population [27]. In our study, this age is slightly higher (18 years old) maybe related to the disease.

Finally, in an overall approach to SH, it is difficult to separate the emotional part, the psychosocial skills, and the mechanical part of sexuality. There are real needs: approximately three-quarters of patients and parents wanted HCPs to be proactive on the subject. Only one quarter of patients felt able to address the issue, but nearly two-thirds thought it was important to raise the subject during adolescence. Even in an era of patient education, HCPs are still uncomfortable addressing the subject [28].
Looking for similar studies in other chronic diseases of adolescence (asthma, diabetes, inflammatory bowel disease, adolescents and young adults with cancer) we found one qualitative study on SH from 2018 in the US on adolescent girls with cystic fibrosis and their parents [29]. A cross-sectional survey of adolescents with cancer and HCPs in the Netherlands in 2020 is also published [30]. The findings are in line with ours: most reported that they had never discussed SH, including the impact of the disease and treatment, in the context of care. There are also parental barriers to talking about it with adolescents (lack of knowledge, difficult emotional context, and cultural barriers). In these two articles, like in our study, young people stated being interested in digital resources (videos, smartphone applications) and in being able to talk with peers to gain a sense of normality. An interesting point of the study on cystic fibrosis is how the digital resources were accessed: it was seen as preferable to deal with SH on a general adolescent SH website and then focus on the specific features related to the disease to provide visibility of the issues to the entire adolescent population [29]. In an era of mediating consent and promoting empathy in sex education [31], this would enable adolescents without chronic diseases to better understand the experiences and constraints of illness and treatment. Following the example of the educational series for teenagers "Sex Education" on the Netflix platform, which addresses topics such as sexual orientation or sexual dysfunction, we could envisage including protagonists with chronic diseases who find positive outcomes in their love and sex lives [32].

Santé Publique France (a national agency under the Ministry of Health) conducted a project in 2021 to list reliable sites for sex education [33] with content about the right to be different [34], together with an international program on sex education [35]. It would be of interest to expand this type of collection with testimonies from adolescents with chronic diseases. The promotion of scientifically validated sites adapted to the age group could also reassure parents who may not see digital tools or assistance from a peer expert as useful sources of information. Online resources would also meet adolescents’ wish to access information without their parents being informed and to ask questions anonymously. Some materials are thus appearing very gradually in sex education media [34]. The use of digital materials designed for adolescents does seem to be a useful learning vehicle for the promotion of overall health and sexual health in particular [36–39].

School-based workers such as nurses should also have an awareness of SH in adolescents with chronic diseases and the resources available [40]. However, digital resources alone cannot meet all the needs of adolescents and their parents. Besides general information related to the disease, young people need to discuss, be reassured and be listened to.

The hospital was the preferred place for this process. However, although love life seemed to be more strongly affected than sex life among these adolescents, we see that the HCPs focused on the biomedical aspects. We can also assume that pediatric rheumatologists are reassuring figures for both children and their parents, as a relationship has been established over time with someone viewed as an expert on the disease. However, these HCPs did not seem sufficiently proactive on the issue. There are certainly several reasons for this: a lack of training, difficulty broaching this subject with a young person they may have watched grow up. Sometimes, the adolescents may be shy of on these issues. Presence of parents should not be a problem as, in adolescence, consultations without them are recommended [22].

A previous study on the needs in SH for chronic inflammatory rheumatism [28] enables us to target the training needs of HCPs, and can help us propose a course specifically adapted to this issue [41].

We note the confidence that more than half of patients have in sexologists in outpatient practice. The presence of a hospital sexologist would allow a transition, after a professional has approached the subject and not been able to go further. Although parents today do not seem to give this specialty much credit, a change in mentalities is likely, as today’s children are tomorrow’s parents.

The study has some limitations, mainly the overrepresentation of women and persons with higher levels of education compared to the general population at the same age in France [42].

We can assume that persons with stronger communication and comprehension skills and with higher educational levels were more likely to answer a long questionnaire [43, 44].

The overrepresentation of women is not surprising, they are often in the majority in most subtypes of JIA and particularly for the more severe forms that may require adult management (especially polyarticular form with rheumatoid factor) [3].

Moreover, it is already known that women with higher levels of education tend to participate more actively in health surveys [43, 44]. Finally, based on the fact that most JIA women responded, it may be that the mother-daughter relationship influenced the gender of the responding parent.

Finally, for sensitive issues such as sexuality, participation rates may be lower [45]. However, the higher levels of confidentiality allowed by anonymous filling out of the questionnaire used in our study provided a real opportunity to reveal truthful information [46]. The fact that fewer parents responded could be explained by the method of distribution (the children had to ask their parents to take part in the study). Finally, there is probably a generational barrier, SH having only recently gained momentum and media exposure.

**CONCLUSION**

HCPs should address this unmet need for SH in hospital.
The results suggest practical steps to address a key problem of adolescence, which may be extended to chronic diseases other than JIA:

- Incorporate SH specifics of adolescents with chronic disease into accredited SH education websites and school-based sex education programs generally.
- Train hospital HCPs and school nurses in SH so that they are proactive on the issue.
- Integrate a peer expert into patient education offers,
- Have a sexologist in hospital facilities,
- Educate parents about the resources available to their children.

**Abbreviations**

HCP  
healthcare provider

SH  
sexual health

**Declarations**

**Ethics approval and consent to participate**

All procedures complied with ethical standards and the Declaration of Helsinki.

**Consent for publication**

Not applicable

**Availability of data and materials**

Data are available from the corresponding author on reasonable request.

**Authors’ contributions**

CSa designed the study, collected, and analyzed the data, and drafted the manuscript. AC collected and analyzed the data, and drafted the manuscript. PB and CGA carried out the statistical analyses and reviewed and revised the manuscript. LC, BF, PGa, PGu, GH, DL, EM, NP, CSo, ST, AT and SM were involved in the data collection, revised the manuscript, and approved the final version. JDC made a substantial cultural contribution and reviewed and revised the manuscript. All the authors read and approved the final version.

**COMPETING INTERESTS**

None of the authors have any competing interests to declare in relation to this manuscript.

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**References**


Figures
Figure 1

Flow chart of survey participants
Figure 2

Supports best suited to addressing SH according to juvenile idiopathic arthritis patients and parents.

SH: sexual health.

Figure 3

The most competent HCPs (A) and the most approachable HCPs (B) to address SH in hospital with juvenile idiopathic arthritis adolescents, according to patients and parents.
HCP: healthcare provider; SH: sexual health.

**Supplementary Files**

This is a list of supplementary files associated with this preprint. Click to download.

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