

Original article

Use and perceived relevance of health-related Internet sites and online contact with peers among young people with juvenile idiopathic arthritis

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Abstract

Objective. To evaluate the frequency of use and relevance of health-related Internet (HRI) sites and online peer support groups and their association with demographic, disease-related and psychosocial variables in young people with JIA.

Methods. In a cross-sectional study, 176 young people (10–27 years of age) with JIA were asked to complete a questionnaire. The frequency of using HRI sites (regarding information, medication use and aspects of JIA relating to social life), online peer contact and perceived relevance of HRI sites and online peer communication were determined. Associations with demographic variables, disease activity, medication, emotional behaviour and coping were also examined.

Results. Seventy-one per cent of the 142 respondents had used the Internet to search for general information on JIA, but specific topics, such as medication, were searched for less often. Twenty-five per cent of respondents had visited a forum or had contacted peers online. The perceived relevance of HRI sites and online peer contact was rated low (median 2.0 and 1.0, respectively; scale 0–10). Apart from female gender ($P < 0.01$), none of the demographic and disease-related factors were associated with HRI site use. Coping styles, confrontation and reassuring thoughts were associated with increased HRI site use, but only in males. Internalizing and externalizing problem behaviour were not significantly associated.

Conclusion. The frequency of HRI site use among young people with JIA was less than expected and was considered of low relevance. HRI sites in their present form cannot replace traditional information as an additional source to increase knowledge.

Key words: adolescent rheumatology, juvenile idiopathic arthritis, transition, digital information, coping factors, education (patients), DMARDs

Rheumatology key messages

- The relevance of health-related Internet sites and online contact with peers in patients with JIA is rated low.
- Disease-related factors cannot be used to identify young people with JIA using health-related Internet.
- Coping in male JIA patients is associated with increased health-related Internet use.

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Introduction

JIA is a chronic inflammatory disease of the musculoskeletal system that affects children before the age of 16 years [1]. Due to persistent disease activity and impaired functional outcome, a large proportion of these young people will experience the consequences of JIA into adulthood and will need to manage their health condition independently [2–5]. In adults with a chronic disease, it is known that increased knowledge and self-management improve

health outcomes and quality of life and reduce the use of medical treatments [6–8]. Whether the same holds true for young people is suggested but not known [9]. Nevertheless, it is standard procedure in many hospitals, including ours, to provide young people with JIA and their parents with information about their disease and prescribed medication.

Several programmes have been developed for adults with chronic diseases to increase knowledge and self-management. Education about a disease and its therapies is given in verbal and written formats, as well as in group programmes containing social, cognitive and behavioural therapy [10]. Information, peer support groups and disease-oriented social networks are also accessible via the Internet. This is in line with the increasing availability and use of the Internet [11–14]. Advantages of Internet-based health-related information over personal contact or printed brochures include easier accessibility, anonymity, easier updating and reduced cost [15]. Studies have shown that adult patients using health-related Internet (HRI) sites or online peer support groups feel empowered in managing their health, communicate with their physicians and participate in making decisions about treatment and improve their self-management skills [16, 17]. Using the Internet may be beneficial to the patient in physical and psychological terms as well as increasing their contact with the physician, and may positively influence consultation time and compliance and reduce costs. Female gender [18, 19], younger age, higher education and income and the presence of other chronic conditions are associated with frequent HRI use [20]. Controversy exists about whether patients with higher disease activity and lower functional status are more willing to use the Internet to keep in contact with their peers [21]. The association between psychological variables and HRI use has rarely been investigated. It has been suggested that adult patients with poor mental health use the Internet more often [20].

Several web-based applications for adolescents and young people with JIA have been developed [22–24]. When evaluating one of these it was found that only 27.9% of eligible patients used the website. From this selected group, only 15.9% continued to use the portal account [23]. This could be the result of low Internet availability due to the financial circumstances of the study population (Cincinnati, OH, USA). Another explanation could be that adolescents are averse to being different and strive to be normal [25], resulting in avoidance of any health-related information. A recently developed website in the Netherlands for young people with rheumatic diseases aims to be more interactive and provide information about age-relevant topics such as alcohol, sexuality and pregnancy (<http://www.jong-en-reuma.nl>). To benefit from the advantages of Internet-based health information, insight has to be acquired into the frequency of use of and perceived relevance on HRI sites and peer support groups. Preferably this should be studied in a country where Internet availability is high and HRI sites specialized for young people with JIA are available. The Netherlands

is such a country (<http://www.internetworldstats.com>). To our knowledge, information on the use of general and HRI sites by young people with JIA is currently lacking [26].

The aim of this study was to determine the frequency of use and perceived relevance of HRI sites and the opportunities for online contact with peers for young people with JIA. In addition, we investigated which demographic and disease-related variables are associated with frequent Internet use in general and the use of disease-related websites in particular. Finally, emotional behaviour and coping were analysed in relation to the frequency of HRI use. The information obtained in this observational study may assist in identifying those patients who will benefit from Internet-based programmes and websites to increase autonomy and self-management in young people with JIA.

Patients and methods

Study design and patient selection

Between 2005 and 2008 all young people with JIA (as classified by ILAR criteria [1]) between 10 and 27 years of age were asked to participate in an observational cohort study (the Transition Study). Patients were included if they were treated in the outpatient clinics of the paediatric or adult rheumatology departments at the University Medical Centre Utrecht. People younger than 18 years of age were seen by a paediatric rheumatologist and those older than 18 were seen by an adult rheumatologist. All participants first seen before publication of the ILAR criteria for JIA were reclassified using these criteria. The study was approved by the Medical Ethics Committee of the University Medical Centre Utrecht. Written informed consent was obtained from participants older than 18 years of age and from the parents of children younger than 18.

Clinical assessment

Demographic variables (age, sex, level of education), disease characteristics (subtype, age at disease onset, disease duration) and current medication use (systemic CSs and DMARDs, including biologics) were obtained from the medical records. Level of education was divided into three classes: low, medium and high, where low indicates no education, primary school or primary vocational education; middle indicates secondary school or secondary vocational education and high indicates higher vocational education or university.

Clinical assessments made by the paediatric or adult rheumatologist (as appropriate) were the following: Physician's Global Assessment of disease activity measured on a 10 cm visual analogue scale (VAS-physician, where 0 = no activity and 10 = maximum activity); swollen joint count and joints with pain upon movement/tenderness from 71 joints [27]. ESR (mm/h) and CRP (mg/l) were also determined.

Disease activity

Given that participants were recruited from both paediatric and adult clinics, DASs commonly used in both departments were computed. In adult patients, the 28-joint DAS (DAS28) is commonly used and has been validated [28]. This is a weighted compound score of the total number of a selected group of swollen and painful or tender joints (both range 0–28), the Patient's Global Assessment (range 0–100) and the ESR.

Joints with active arthritis in paediatric DASs are defined as those that are swollen and/or painful upon movement (core set criteria) [29]. The 27-joint Juvenile Arthritis Disease Activity Score (JADAS27) [27] is a compound score of the Physician's Global Assessment (range 0–10) plus the Patient's Global Assessment (range 0–10) plus the normalized ESR plus the number of a selected group of joints with active arthritis (range 0–27). The JADAS27 may present an advantage over the DAS28 because it includes measures for the cervical spine, hips and ankles, joints that are often affected in (adult) JIA patients. JIA participants in remission are defined according to the Wallace criteria [30].

Functional ability was assessed using the validated Dutch version of the Childhood Health Assessment Questionnaire (CHAQ), with a score range from 0 to 3 (0 = best and 3 = worst). The CHAQ also includes 100 mm VASs for pain and overall well-being (VAS-global) [31]. There is a lack of agreement between the CHAQ and the version validated in adult patients with rheumatic diseases (HAQ). To make comparisons possible between participants, the CHAQ was also used in participants > 18 years of age [32].

HRI use and perceived relevance

To evaluate general and health-related use of the Internet, a questionnaire was developed similar to the questionnaire evaluating the frequency of HRI site use in adult patients with RA and SSc [20, 33]. The following factors were assessed: access to and general use of the Internet; use of HRI sites; use of online peer support groups and disease-oriented social networks and perceived relevance of HRI sites and online peer contact.

First, participants were asked whether they had access to the Internet. If so, they were asked to rate the frequency of Internet use on a 5-point scale, ranging from never to >3 h each day. General use of the Internet was dichotomized as ≥ 1 h/day (frequent Internet use) and <1 h/day (non-frequent use).

The frequency of HRI use regarding online information about JIA and related items was determined for 14 items (Cronbach's $\alpha = 0.90$). HRI use was scored on a 4-point scale (never, once, several times, regularly) and, for analytical purposes, was dichotomized into non-users (scoring never) and users (scoring once, several times, or regularly). If HRI sites were used, participants were asked in an open question to name their favourite websites regarding rheumatic diseases and chronic illness.

Communication with peers via the Internet (e.g. reading along and posting on a peer support group) and via ways other than the Internet was determined for seven items (Cronbach's $\alpha = 0.74$) and was scored on a 4-point scale (never, once, several times, regularly). A dichotomous outcome (users/non-users) was used in the analysis. If respondents indicated that they communicated with their peers, information was asked as to which peer support sites were used, the frequency of communication, whether they contributed postings and, if so, how many. The perceived relevance of HRI information and contact with peers was determined by rating the importance on a scale from 0 to 10 (0 = not important and 10 = most important).

In order to pilot test the questionnaire, the first six questionnaires were completed by the participants while talking the questionnaire over with a research assistant. This led to some minor changes in the wording of some questions.

Psychological assessment

General psychological functioning was measured by the Youth Self-Report, a self-assessment questionnaire investigating adolescent behavioural and emotional problems. The questionnaire has been translated, standardized and validated in the Netherlands [34]. To evaluate emotional behaviour, three summary scales can be scored: total problems, internal behaviour and external behaviour. Scores are reported in categories: normal, borderline clinical and clinical. As normal values are available for patients aged 10–18 years, only participants under the age of 19 were assessed.

Coping was assessed by the Utrecht Coping List (UCL) for adolescents [35]. This is a self-perception questionnaire, derived from the adult UCL, to identify seven different types of coping strategy. A higher mean total score per coping strategy indicates an increased tendency towards using that specific coping style. Normal values are available for Dutch boys and girls separately [36]. In clinical and research practice the UCL-adolescent is also used in other chronic diseases for patients aged 12–18 years [37–39]. We therefore evaluated the results in male and female participants aged 12–18 years.

Statistical analysis

Descriptive statistics were used to summarize the data. The Kolmogorov–Smirnov test was used to check for normality of the metric data. Comparison of binominal variables was analysed using the chi-square test. Comparison of categorical variables was analysed by a non-parametric analysis of variance (Kruskal–Wallis test). Comparison of continuous variables was analysed with the non-parametric Mann–Whitney U-test, as data were not normally distributed. All statistical tests were two-sided. A *P*-value <0.05 was considered statistically significant. SPSS software (version 20.0; IBM, Armonk, NY, USA) was used to manage and analyse data.

Results

Patient characteristics

A total of 215 young people with JIA were asked to participate; 39 were excluded for various reasons (not willing, $n = 14$; lack of time, $n = 6$; diagnosis other than JIA, $n = 11$; unable to read, $n = 5$; unknown, 3). One hundred and seventy-six individuals gave written informed consent. Of the 176 included, 142 (80.7%) participated in answering the questionnaire. No differences in demographic or disease-related variables were seen between participants and non-participants (Table 1). Two-thirds (69%) of the participants were female. Participants had a median disease duration of 6.8 years [interquartile range (IQR) 3–11 years]. Almost one-third (30.3%) were free of DMARD use. Seventy-nine (56%) participants used one DMARD, 17 (12%) used two DMARDs and three (2.1%) used a combination of three DMARDs. Median disease activity as determined by JADAS27 was 4.2 and by DAS28 was 2.2 (Table 1).

Use of the Internet in general, use of HRI sites and its relevance

Almost all participants [139 (98%)] had access to the Internet. Most participants [110 (78%)] used the Internet every day; only 5 (4%) used the Internet less than once a

week. More than half of the participants [93 (65%)] spent >1 h/day on the Internet and were classified as frequent users.

The majority of the participants [101 (71%)] had at some point used the Internet to obtain information about JIA (Table 2). However, most (66%) reported searching the Internet for rheumatic disease-related information only once or a few times. Just 6% regularly searched for JIA-related information on the Internet (Table 3). The most favoured sites were <http://www.reumafonds.nl> (home page of the Dutch Arthritis Foundation, which, among others, provides information about rheumatic diseases; 27%); <http://www.google.com> (20%); <http://www.jongen-reuma.nl> (a site developed by the University Medical Centre Utrecht for young people with rheumatic diseases; 18%) and <http://www.printo.it> (Paediatric Rheumatology International Trials Organisation; 4%). All these sites are available in different formats, including mobile web for smartphones. Participants mostly searched for information about JIA (its causes and symptoms) and about rheumatic diseases in general. Considerably fewer participants (32–60%) reported searching for other topics, e.g. JIA treatments, education, employment and lifestyle (Table 3). Items related to daily life (school, lifestyle, friends, hobbies) were more frequently visited than those relating to treatment, alcohol, sex and pregnancy (Table 3).

TABLE 1 Demographic variables of participants and non-participants

Variable	Participants ($n = 142$)	Non-participants ($n = 34$)	P-value
Female, n (%)	98 (69)	20 (59)	0.23
Median age (IQR), years	14.6 (6.8)	16.3 (5.3)	0.07
Education, n (%)			0.25
Low	40 (28)	1 (3)	
Medium	28 (20)	3 (9)	
High	40 (28)	1 (3)	
Unknown	34 (24)	29 (85)	
Subtype JIA, n (%)			0.61
Systemic	19 (13)	4 (12)	
Oligopersistent course	34 (24)	8 (24)	
Polyarticular, including oligo extended	78 (55)	16 (47)	
Enthesitis, psoriatic and unclassified	11 (8)	5 (15)	
Missing, n (%)		1 (3)	
Median disease duration (IQR), years	6.8 (8.2)	6.9 (6.6)	0.73
Median disease activity (IQR)			
Active joint count	0.0 (2.0)	0.5 (4.3)	0.41
JADAS27	4.2 (6.9)	4.5 (9.3)	0.58
DAS28	2.2 (1.4)	1.9 (2.3)	0.45
Remission Wallace criteria, n (%)	76 (54)	17 (50)	0.86
DAS28 remission, n (%)	78 (67)	9 (64)	0.68
DMARD use, n (%)			
Current MTX	87 (61)	19 (56)	0.70
Current anti-TNF	17 (12)	4 (12)	1.0
No current DMARD use	43 (30)	14 (41)	0.31
Median CHAQ (IQR)	0.50 (1.0)	0.38 (1.6)	0.35

CHAQ: Children's Health Assessment Questionnaire ($n = 109$; score range 0–3); DAS28; 28-joint DAS ($n = 97$ due to uncompleted visual analogue scale of the patient; score range 0.49–9.3); IQR: interquartile range, 25th–75th percentile; JADAS27: 27-joint Juvenile Arthritis DAS ($n = 97$; score range 0–57).

Regarding online communication, 25% of the participants had ever visited a peer support forum. The preferred forums were <http://www.reumadorp.nl> (peer support for all rheumatic diseases; 60%); <http://www.jeugdreuma.com> (support forum for parents of children with rheumatic diseases; 20%) and <http://www.Youth-R-Well.com> (peer support information and forum for 16- to 30-year-old patients; 20%). Active online communication with peers using general social networks varied from 2 to 20% (Table 2).

On a scale of 0–10, the perceived relevance of the information found on HRI sites was scored with a median of 2.0 (25th–75th percentile 0–5.8). The median score for

perceived relevance of contact with peers was 1.0 (25th–75th percentile 0–4.0).

Association between Internet use and demographic variables

The median age of frequent HRI site users was significantly higher than that of non-frequent users: 15.5 years (IQR 6.5) vs 12.3 (IQR 5.58), $P < 0.01$. Educational level was also significantly higher in the frequent users group ($P < 0.01$). Gender was not related to frequent general Internet use. However, female gender was positively associated with HRI site use, while age and education level were not associated (Table 4).

Association between Internet use and disease-related factors

HRI site use was not associated with subtype of JIA, disease duration or disease activity (Table 4). Also, functionality as measured by the CHAQ was not associated (Table 4). Current and past use of DMARDs (including biologics) were also not related to HRI site use.

Association between HRI site use and emotional behaviour and coping

In male participants reporting HRI site use, the coping strategies confrontation ($P = 0.04$) and reassuring thoughts ($P = 0.00$) were used significantly more compared with non-users. No differences in coping strategies were seen between female HRI site users and non-users. Emotional behaviour was not significantly different between HRI site users and non-users.

Discussion

The majority of young people with JIA (71%) use HRI sites once or occasionally to search for information on general aspects of the disease. This is comparable to young people with other chronic diseases and adults who have

TABLE 2 Frequency of Internet use, HRI site use, contact with peers and perceived relevance rate

Variable	Value
Frequency of Internet use, <i>n</i> (%)	
<1 h/day	49 (35)
≥1 h/day	93 (65)
HRI site use, <i>n</i> (%)	
Information on JIA	101 (71)
Visit a forum	36 (25)
Using a chatbox	16 (10)
Using MSN	27 (20)
Mailing group with peers	3 (2)
Mailing private with peers	20 (15)
Read a weblog of a peer	15 (11)
Contact with peers not via the Internet, <i>n</i> (%)	38 (27)
Relevance of HRI sites (<i>n</i> = 120; scale 0–10), median (IQR)	2.0 (5.8)
Relevance of contact with peers (<i>n</i> = 119; scale 0–10), median (IQR)	1.0 (4.0)

n = 142. HRI: health-related Internet; IQR: interquartile range, 25th–75th percentile; MSN: Microsoft Network.

TABLE 3 Frequency of items searched for on HRI sites

Have you looked for information on the Internet about	Never, <i>n</i> (%)	Yes, once, <i>n</i> (%)	Yes, sometimes, <i>n</i> (%)	Yes, regularly, <i>n</i> (%)	Missing, <i>n</i> (%)
Disease causes and symptoms	36 (25)	42 (30)	24 (17)	3 (2)	37 (26)
Rheumatic diseases in general	41 (29)	58 (41)	35 (25)	8 (6)	0
Living with JIA	56 (39)	32 (23)	14 (10)	3 (2)	37 (26)
JIA and school or university (education)	65 (46)	23 (16)	14 (10)	3 (2)	37 (26)
JIA and hobbies or sports	66 (47)	22 (16)	12 (9)	4 (3)	38 (27)
JIA and home adjustments	72 (51)	23 (16)	8 (6)	2 (1)	37 (26)
JIA and relation with family and friends	75 (53)	24 (17)	5 (4)	1 (1)	37 (26)
JIA and treatments	75 (53)	14 (10)	12 (9)	3 (2)	38 (27)
JIA and employment	78 (55)	14 (10)	44 (8)	2 (1)	37 (26)
Alternative treatments	86 (61)	8 (6)	9 (6)	2 (1)	37 (26)
JIA and alcohol and drugs	90 (64)	13 (9)	1 (1)	1 (1)	37 (26)
JIA and pregnancy	92 (65)	8 (6)	3 (2)	2 (1)	37 (26)
JIA and sexuality	96 (68)	5 (4)	2 (1)	2 (1)	37 (26)

n = 142. HRI: health-related Internet.

TABLE 4 Differences between users and non-users of HRI sites

	Users of HRI sites in relation to JIA	Non-users of HRI sites in relation to JIA	P-value
Female,* <i>n</i> (%)	77 (76)	21 (51)	0.01
Median age (IQR), years	14.8 (7.1)	14.0 (5.0)	0.31
Level of education (<i>n</i> = 108), <i>n</i> (%)			0.47
Low	27 (36)	13 (41)	
Medium	19 (25)	9 (28)	
High	30 (40)	10 (31)	
Subtype JIA, <i>n</i> (%)			0.11
Systemic	13 (13)	6 (15)	
Oligopersistent	21 (21)	13 (32)	
Polyarticular	57 (56)	21 (51)	
Other	10 (10)	1 (2)	
Median disease duration (IQR), years	6.8 (9.1)	7.0 (6.8)	0.80
Active joint count, median (IQR)	1.0 (2.0)	0.0 (2.0)	0.18
JADAS27, median (IQR)	4.7 (7.0)	2.7 (7.7)	0.17
DAS28, median (IQR)	2.3 (1.5)	2.0 (1.2)	0.12
Remission (Wallace), <i>n</i> (%)	50 (50)	26 (64)	0.19
DAS28 remission, <i>n</i> (%)	67 (66)	31 (76)	0.38
CHAQ, median (IQR)	0.63 (1.01)	0.38 (0.88)	0.61
Emotional behaviour internalizing, (<i>n</i> = 108)			0.64
Normal, <i>n</i> (%)	58 (76)	25 (78)	
Borderline, <i>n</i> (%)	2 (2.6)	4 (13)	
Clinical, <i>n</i> (%)	16 (21)	3 (9.4)	
Emotional behaviour externalizing (<i>n</i> = 108)			0.37
Normal, <i>n</i> (%)	74 (97)	30 (94)	
Borderline, <i>n</i> (%)	2 (2.6)	2 (6.2)	
Clinical, <i>n</i> (%)	0 (0)	0 (0)	
Emotional behaviour total (<i>n</i> = 108)			0.08
Normal, <i>n</i> (%)	60 (79)	20 (63)	
Borderline, <i>n</i> (%)	14 (18)	11 (34)	
Clinical, <i>n</i> (%)	2 (2.6)	1 (3.1)	
Social competence score, median (IQR)	9.6 (2.5)	8.5 (1.7)	0.22
Coping male (<i>n</i> = 25), <i>n</i> (%)	11.0 (44)	14.0 (56)	
Confrontation,* <i>n</i> (%)	13.0 (2.0)	11.0 (3.0)	0.04
Palliative reaction, <i>n</i> (%)	18.0 (5.0)	14.5 (7.0)	0.25
Avoidance, <i>n</i> (%)	17 (8.0)	17 (10.0)	0.63
Seeking social support, <i>n</i> (%)	11.0 (4.0)	9.5 (5.0)	0.40
Passive reaction pattern, <i>n</i> (%)	8.0 (5.0)	6.0 (4.0)	0.56
Expressing emotions, <i>n</i> (%)	6.0 (2.0)	5.5 (5.0)	0.29
Reassuring thoughts,* <i>n</i> (%)	13.0 (6.0)	6.0 (2.0)	0.01
Coping female (<i>n</i> = 64), <i>n</i> (%)	50.0 (78.0)	14.0 (22.0)	
Confrontation, <i>n</i> (%)	14.0 (6.0)	14.0 (6.0)	0.83
Palliative reaction, <i>n</i> (%)	19.5 (5.0)	18.5 (6.0)	0.85
Avoidance, <i>n</i> (%)	15.0 (4.0)	14.0 (5.0)	0.89
Seeking social support, <i>n</i> (%)	14.0 (5.0)	14.0 (6.0)	0.97
Passive reaction pattern, <i>n</i> (%)	9.0 (4.0)	9.0 (2.0)	0.24
Expressing emotions, <i>n</i> (%)	6.0 (2.0)	6.5 (2.0)	0.99
Reassuring thoughts, <i>n</i> (%)	10.0 (4.0)	10.5 (5.0)	0.71

n = 142. **P* < 0.05. CHAQ: Children's Health Assessment Questionnaire (*n* = 127; score range 0–3); HRI: health-related Internet; IQR: interquartile range; JADAS27: 27-joint Juvenile Arthritis DAS (*n* = 117 due to missing VAS score; score range 0.49–9.3).

RA [19, 20, 33]. The perceived relevance of HRI sites, however, is rated low (median score 2.0).

The Internet in general is widely used: 65% use it for > 1 h/day. In line with the literature [20, 40], we found that higher education level and older age are significantly associated with more Internet use. Only five of our respondents use the Internet less than once a week. They

are not different from other participants according to demographic and disease-related variables.

In some studies, frequent use of the Internet is associated with HRI site use [40]; however, we found no correlation. In the literature, demographic variables associated with HRI site use are female gender, educational level and age [20, 41]; in our study, only female gender

was associated with HRI site use. Disease-related factors are not associated with HRI site use. This is in contrast to what we expected, as patients with high disease severity, short disease duration and more medication use need more tools to manage their disease [42, 43].

Only general information about JIA is searched for. Specific information, e.g. treatments and issues related to daily life, is searched for considerably less. Young people seem to be least interested in topics such as pregnancy, sexuality, alcohol and drugs. This is in contrast to qualitative studies performed in adolescent JIA persons, where a desire was reported for more information on medical treatment and lifestyle management [25, 43, 44]. Distinct study designs, using focus groups or face-to-face interviews with a selected group of patients, might explain the differences. Another explanation may be that young people do not feel completely at ease when searching pregnancy or alcohol, if they suspect their parents might monitor their Internet use.

The perceived relevance of HRI sites and of contact with peers is rated low, which was recently confirmed in adolescents with other chronic diseases [19, 41, 45, 46]. It may be that young people do not want to know (too many details) about or do not want to be occupied with their disease [25, 47]. Our hypothesis to explain the perceived low relevance of HRI site use in young people is that in general the pubertal brain (prefrontal cortex, which affects judgement, impulse control and long-range planning) is relatively late in reaching adult maturity [46]. Long-term planning is lacking, and young people with JIA may be striving for normality with their peers (they do not wish to be labelled sick or disabled), resulting in denial of any consequence of the disease and an unwillingness to absorb disease knowledge [25, 47]. It is suggested that the ability to imagine future consequences and adolescent development are different in teenagers with chronic conditions compared with healthy peers, but more research is needed to confirm this [48]. An alternative explanation for the low use and low perceived relevance may be that seeking online information is not the primary strategy. More traditional methods of information gathering, e.g. during consultations, are perhaps sufficient, as also noted by some participants ('I get enough information from my doctor') [47]. Lack of confidence in the reliability of available sites or discontent with their format may also play a role [45, 47]. Indeed, others have found that many sites for young people with chronic diseases are not reliable [45]. We believe most of the favoured JIA sites in our study are reliable, since these were developed in collaboration with young people with JIA and paediatric health care providers (e.g. <http://www.reumafonds.nl> and <http://www.jong-en-reuma.nl>). Yet, a significant number of participants—who mentioned Google as their favourite website—might end up at unreliable sites. Therefore, supporting young people in developing e-health literacy is essential [45]. To what extent the sites are appealing to young people regarding content, design and platform [49] was not evaluated, and this might be interesting for future studies [45].

Evidence suggests that the use of HRI sites is influenced by coping and emotional behaviour [39]. We show that in male respondents the active coping strategy confrontation is used significantly more in HRI site users compared with non-users. Seeking social support and emotional expression are not different in male participants; no differences in coping were found in female HRI site users and non-users.

We expected a higher proportion of participants with internalizing behaviour to be using HRI sites. However, in our study no differences between HRI site users and non-users were observed. We conclude that coping and emotional behaviour cannot explain the low frequency of HRI site use and its low perceived relevance.

This study describes the frequency of general and HRI site use and the association with demographic and disease-related factors and coping and emotional behaviour. Results are similar in young people with other chronic diseases [19, 41]. Our study group is representative of a tertiary outpatient clinic of paediatric and adult rheumatic diseases, since all patients were invited to participate and response was high. The participants have established disease (disease duration of 6.8 years) and low disease activity. HRI site use might be different in newly diagnosed JIA patients and in those with active disease where medication changes are necessary. However, we have not found associations between disease duration, disease activity and HRI site use. Results might also differ when an HRI site is actively promoted in ways other than during consultations (Short Message Service or mobile applications) or when an HRI site is more specifically adapted to the patients' needs or is made more attractive (e.g. educational games). To answer these questions, qualitative studies on young peoples' needs and wishes regarding content, format and design as well as evaluation of existing sites are needed. Due to the cross-sectional design, no information was obtained or can be concluded about the effect of (or not) using HRI sites. More research is needed in comparing prospective intervention studies in order to evaluate the effect of active Internet use on disease outcome and self-management.

In conclusion, the frequency of HRI site use is lower than expected and its relevance is rated low. Currently offered HRI sites are not suitable as the only source of information for young people with JIA when aimed at increased knowledge and self-management in the critical period of adolescence and young adulthood.

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