



Original article

## Distressed and Looking for Help: Internet Intervention Support for Arthritis Self-Management



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### A B S T R A C T

**Purpose:** Focusing on youth with juvenile arthritis (JA), this study investigates eHealth interventions as a means to develop services to improve the health of youth with chronic conditions. Internet use and preferences for Internet-based interventions were compared among youth with high and low psychosocial quality of life (PS-QL) scores.

**Methods:** Youth with JA (n = 134; high PS-QL, n = 67; low PS-QL, n = 67) completed the MyRheum online survey, which assessed physical functioning, psychosocial health, Internet usage, and amount of time spent using social networking Web sites. Youth indicated their choice, interest, and preferences in using a Web site for youth with JA. The *t* tests, chi-squared tests, and Fisher exact tests were used to assess significance between high and low PS-QL groups.

**Results:** Youth with lower PS-QL reported greater intrusiveness of their condition across life's activities than did youth with higher PS-QL. Low PS-QL was associated with spending more than 1 hour per day using social networking sites and having used the Internet to find information on various health and substance use topics. Youth with lower PS-QL expressed more interest in messaging others, online forums, building personal profiles, and networking with other teens than did youth with higher PS-QL. Both those with high and low PS-QL preferred online to in-person support groups.

**Conclusions:** Many youth with JA report low PS-QL and identify interest in Internet-based supportive interventions. The next generation of eHealth interventions for youth with JA, and possibly other chronic conditions, may better address their needs by recognizing the diversity of experiences and tailoring intervention strategies accordingly.

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### IMPLICATIONS AND CONTRIBUTION

Policy workers and health practitioners should recognize that youths' interests span multiple platforms. Programming should be flexible to meet changing interests and shifts in adolescent development. Practitioners must be prepared to provide a broad range of strategies and opportunities, meeting youth where they are and helping them succeed.

eHealth interventions, the integration of information and communication technology, offer the opportunity to improve the

health of youth who have been hard to reach and engage in clinic-based health programs [1,2]. Applying eHealth interventions in adolescent health is appealing because adolescents tend to be early adopters of new technologies and quickly incorporate them into their lives, technologies can offer real-time support, and youth tend to prefer technology-delivered interventions to traditional face-to-face interventions [3]. Yet, despite this appeal and over a decade of innovation, there appears to be only a handful of published reports that demonstrate the effectiveness of eHealth

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interventions for youth with chronic conditions [4–6]. Drawing on the current conceptualization of health care quality as delivering the right treatments to the right patients at the right time [7], we examine the opportunities to improve the quality of eHealth interventions by examining the match between intervention strategies and the needs of adolescents with chronic conditions. This study was part of a larger study of youth with arthritis toward the goal of developing a targeted intervention. E-Health interventions provide an opportunity to improve the lives of youth with chronic conditions by expanding on the reach and depth of traditional clinic-based approaches [4]. For example, eHealth interventions can be accessible when and where youth prefer, and thus overcome the issues of busy lives and geographic isolation. Many youth do not have reliable access to care that is expert and developmentally appropriate. Finally, eHealth interventions have the capability of expanding health care and health education into the areas of social support.

In this study, we examine an eHealth intervention for youth living with juvenile arthritis (JA) given its relevance specifically for these youth and as an exemplar for developing services for youth with chronic conditions more broadly. Growing up with JA, as for youth with many chronic conditions, has improved through decades of advances in medical treatments and increasing accommodations in community settings. Yet, there is still no cure for JA. Most adolescents with JA will live with symptoms, require treatments in adulthood, and have special needs which are often unaccommodated [8–11]. Nearly all aspects of life are affected by episodes of inflammation, pain, frequent therapies, infusions and injections, medication side effects, and activity restrictions [4,8–11]. The social and emotional impact of JA becomes more apparent during adolescence as the symptoms and treatments compete with developmental tasks of youth at different ages and their families [8–11]. Adolescents, their families, and health care providers find it understandably challenging to balance the tasks of managing JA and pursuing opportunities for cognitive, emotional, and social development [8–12]. For these reasons, adolescents with JA report considerably poorer physical and psychosocial quality of life (PS-QL) than do their peers [8–14].

The purpose of this study was to inform innovative eHealth program development by describing and comparing Internet use and preferences for information and support between youth with JA who report low or high psychosocial health as established by scores on the PedsQL (Mapi Research Trust, Lyon, France) [15].

## Methods

### Participants and procedures

This study uses data from the MyRheum survey of youth with JA. The survey included questions about general and arthritis-related health, health care use, quality, and satisfaction. The survey also included topics pertinent to youth growing up with JA (e.g., nutrition and fitness, risk behaviors, and sexual and mental health). Detailed recruitment and study procedures have been previously described [16]. Adolescents who have arthritis ( $n = 134$ ) completed an online survey. We recruited potential participants by posting flyers and notices in pediatric rheumatology clinics, at events and on the Web sites sponsored by advocacy organizations (Arthritis Foundation of Minnesota and of Wisconsin), and through targeted advertisements on Facebook. Recruitment materials stated that youth with JA were being sought to participate in a study about their

health and health care experiences. Additional eligibility criteria included youth aged 14–19 years who lived in the United States. Online informed consent was obtained from the participants themselves, after which they completed the online survey. Data were collected between June and December 2010. Gift cards (\$10.00) were provided to adolescents who completed the survey. The Institutional Review Board of the University of Minnesota approved all study protocols, including a waiver of the requirement for parental consent.

### Measures

Youth were asked to self-report their sex (male/female), age (in years), race and ethnicity, and the specific type of inflammatory disease with which they were living (later recoded as JIA vs. other). In addition, respondents reported whether they were living with both of their parents or had another living situation (e.g., living independently), and the degree to which their illness was intrusive in their daily lives as measured by the 13-item Illness Intrusiveness Scale adapted for this study to reflect the contexts of the lives of adolescents [17].

The PedsQL 4.0 Short Form 15 is a frequently administered measure of health-related quality of life. We used the 10-item psychosocial health summary score to identify youth who may benefit most from online social support interventions [15]. The psychosocial summary score is comprised of the average of the items in the emotional, social, and school functioning scales [15]. In our sample, the psychosocial health summary score demonstrated good reliability,  $\alpha = .88$ .

Participants reported the amount of time on average they used social networking Web sites each day (none, 5–30 minutes, 30 minutes–1 hour, 1–3 hours, more than 3 hours). Next, the frequency (none, once or twice, or 3 or more times) in which adolescents tried to find information on the following topics in their lifetime was assessed: (1) fitness or exercise; (2) nutrition; (3) puberty; (4) sexual health; (5) fighting or bullying; (6) tobacco use; (7) alcohol or other drugs; (8) mental health; (9) dating violence or rape; and (10) other health topics.

Finally, participants reported whether they would use a social networking Web site for teens with arthritis using a four-point scale with responses ranging from strongly disagree to strongly agree. Interest in various features of social networking Web sites (e.g., instant messaging, message boards, and forums) for teens with arthritis was assessed with three-point scales (not at all interested, somewhat interested, or very interested). Preference for online or in-person weekly support groups was also assessed.

### Analysis plan

For ease of interpretation and comparison with previous studies, a median split classified participants' scores on the PedsQL psychosocial health summary (PS-QL) as low or high (median, 63.19; range, 0–100). There is no established cutoff score on the PS-QL that defines poor psychosocial functioning and in these data, there was no natural break in the distribution of scores; thus, the median provided an unbiased point resulting in adequate sample sizes for making comparisons with 50% of participants in each group (high PS-QL group,  $n = 67$ ; low PS-QL group,  $n = 67$ ). Higher scores indicate better quality of life. Self-reported demographics, Internet use, and interest in social networking Web sites were assessed for statistical significance between high and low PS-QL groups with  $t$  tests, chi-squared

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