Internet Sites Offering Adolescents Help With Headache, Abdominal Pain, and Dysmenorrhoea: A Description of Content, Quality, and Peer Interactions

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Objectives   To analyze content and quality of headache, abdominal pain, and dysmenorrhoea websites, and to thematically analyze online pain forums.   **Methods**   Websites offering support, advice, or information regarding pain were explored. Websites were analyzed quantitatively using the Health-Related Website Evaluation Form and the DISCERN scale. Websites containing forum functions were thematically analysed assessing how the Internet is used for support and advice.   **Results**   63 websites were included. Few websites scored in the upper quartiles of scores on the measures. 7 websites contained supportive posts, pertaining only to dysmenorrhoea. The ways users cope and the coping judgements of other forum users are presented thematically. 3 themes emerged: (1) passively engaged postings, (2) actively engaged postings, and (3) reactively engaged postings.   **Conclusions**   Internet pain resources are of low quality and questionable value in providing help to adolescents. Future research should explore how to improve quality.

Key words   abdominal pain; content analysis; dysmenorrhoea; headache; information seeking; online pain material; support seeking; teenagers; thematic analysis; user perspective.

Introduction

Studies of adolescent coping have found that gathering information and seeking social support are common coping strategies employed by young people in pain (Reid, Gilbert, & McGrath, 1998). Where it is available, adolescents use the Internet as a primary source of information gathering, including searching for health-related information (Suzuki & Calzo, 2004). Despite the ubiquity of this coping strategy, little is known about quality or purposes of the content adolescents are likely to find online. Previous studies with adults have found pain-related information available online to be of poor quality (Corcoran, Haigh, Seabrook, & Schug, 2009).

The Internet is a relatively unregulated informational environment. Its benefits are that it can provide access to information for adolescents who were previously geographically excluded and it can enable social support networks with other adolescents in pain (Long & Palermo, 2009; Ritterband & Palermo, 2009). The challenge of the Internet is that it is difficult if not impossible to control the nature or quality of the content using any traditional quality control processes developed for other media (Silberg, Lundberg, & Musacchio, 1997), although some attempts have been made, such as ''HonCode''—a rating of online health information promoted by WHO as an indicator of website quality (Boyer, Selby, Scherrer & Appel, 1998).

Healthcare professionals cite apprehension about information accuracy as the primary reason for reluctance to recommend websites to patients over traditional information sources (Podichetty & Penn, 2004). Existing

evaluation of adult online information relating to chronic pain (Corcoran, et al., 2009) and specific pain such as headache (Peterlin, Gambini-Suarez, Lidicker, & Levin, 2008) have rated online information as poor. We would expect the same to be true for online materials directed at adolescents with chronic and recurrent pain.

Information seeking and social sharing are primary motivational features of being in pain. When faced with pain people will seek first an explanation, and second the optimal method of pain management (Crombez, Eccleston, Damme, Vlaeyen, & Karoly, in press). Despite the doubts of health care professionals about developing e-resources (Podichetty & Penn, 2004), young people will search for help, and will use methods readily available to them; for many this means going online (Corcoran, et al., 2009; Corcoran, Haigh, Seabrook, & Schug, 2010). Independent use of information seeking increases with age, but it is known that adolescents are actively engaged in pain management strategies, including the use of over the counter medicines stored in the home, and information seeking from as young an age as 11 years (Chambers, Reid, McGrath, & Finley, 1997). Indeed, adolescents are more likely to use the Internet as a platform for information gathering if the health condition they are interested in is considered embarrassing or stigmatising (D'Auria, 2011) as may be the case with dysmennorhea or abdominal pain.

In light of these issues, the current study was designed to investigate: (a) what information is available to UK adolescents searching the internet for common pain problems, (b) to assess the quality of the information on the recovered sites, and (c) to investigate the dominant themes where "posting" facilities are available for the social sharing of pain advice. The primary aim of this study was to describe the content and quality of information available to teenagers as it appears online for three common adolescent pain complaints: dysmenorrhoea, (Davis & Westhoff, 2001; Rapkin & Mikacic, 2008) headache, and abdominal pain (Perquin et al., 2000). First, we ran an Internet search using common phrases and search teams devised by young people. Second, we collated a list of websites purporting to offer help to young people in pain. Third, we analyzed the content of these websites in terms of their provenance, content, quality, readability, and suggestions for treatment (Corcoran et al., 2009). Finally, recognizing that some websites go beyond information, providing opportunities for social sharing and information exchange, we undertook a thematic analysis of any website with a forum function.

Methods
Internet Search and Website Identification

Ethical approval for the study was granted by the institutional ethics committee of the University of Bath. Previous searches of this type have identified websites systematically, but we wished to focus on what adolescents might find online. Search terms that may commonly be used by adolescents were constructed by asking a convenience sample of four healthy, community based adolescents and three research staff with experience of adolescent pain and e-health to generate search terms pertaining to online information seeking in pain. Twenty-one phrases to describe pain and 11 phrases on coping with or managing pain were generated during face to face meetings. Care was taken to use the language adolescents endorsed and said they would use were they searching for information. The final search strings were:

- ("sore" OR "uncomfortable" OR "throbbing" OR "ache*" OR "pain" OR "hurt") AND ("help" OR "cure" OR "remedy" OR "medicine") AND ("period pain")
- ("sore" OR "uncomfortable" OR "throbbing" OR "ache*" OR "pain" OR "hurt") AND ("help" OR "cure" OR "remedy" OR "medicine") AND ("headache")
- ("sore" OR "uncomfortable" OR "throbbing" OR "ache*" OR "pain" OR "hurt") AND ("help" OR "cure" OR "remedy" OR "medicine") AND ("stomach")

Search engines were chosen on the basis of their popularity with users (Nielson, 2010). The three most common were used: Bing (www.bing.co.uk), Google (www.google.co.uk), and Yahoo (www.yahoo.co.uk). These three were used in 91.8% of previous consumer searches. We used the .co.uk functional on all search engines in order to generate more pages from the UK as our focus was to assess what a UK adolescent would find online. Each string was entered into a search engine individually. The first 20 web pages excluding sponsored sites were assessed for inclusion in the analysis giving a total of 180 websites (60 per type of pain) as used in other studies of this sort (e.g., Stinson et al., 2011). Searches were carried out over a five day period in July 2010 and coded for primary inclusion during this time.

Websites were included if they were written in English, were not a scholarly article, advertisement or book chapter, were openly accessible without a password or subscription and contained information relating to the pain the search

focused on. The site had to describe information on causes of pain, descriptions of pain, and pain management methods. These criteria were similar to those employed in previous online content analyses (Khazaal, Chatton, Cochand, & Zullino, 2008). This methodology was supported by feedback from the adolescents who generated search terms, they indicated that they would search ''why they had the pain'' (cause) ''what the pain should feel like'' (symptom) and ''how to fix it'' (management). All websites were identified and coded for inclusion by the first author. This was then validated through assessment by the second author of 20% of the search pool chosen at random. Inter-rater reliability for headache was 100%, for abdominal pain was 83.3% and for dysmenorrhoea was 91.7%. Overall agreement scored 91.7%. Disagreements were settled through discussion between the first and second authors.

Website Content

Data extraction was carried out on all included websites. A coding scheme was adapted from previous studies (Khazaal et al., 2008) and designed to include information on website provenance, description of function and level of interaction. Provenance data included the search engine the website was recovered from, the date it was posted online (if available), presence of a HonCode badge and the organizational type of the website—medical (trust or other healthcare sources), media (newspapers, television etc.), for profit (companies who sell something relating to healthcare or pain management), not-for-profit (charities), educational or forum (blogs, question and answer sites, and interactive forums). We wished to collect data on the type of website as this has been hypothesized in previous studies to be a factor in the quality of information (Corcoran et al., 2009). All websites which didn't readily fit into each of these categories were coded as ''other.'' URLs for each website type, excluding those that were included in the thematic analysis in order to protect the identity of posters are listed in table one (see Supplementary Table). On the data extraction sheet, websites which contained peer-to-peer interactions were noted and prevalidated measures of quality employed. We recorded the primary treatment recommendations of the websites for each pain—i.e., medical, natural remedies, prevention, behavioral, or multimodal (containing more than one treatment type). All data extraction was carried out by the first author and 20% of this was validated by the second author. All websites with a forum function were identified by the

first author and inclusion was then agreed upon by the first and second authors.

Website Quality Assessment

Two previously validated questionnaire measures of the quality of online health information were used. First, the DISCERN measure was designed for use by laypersons to assess quality of health information online, particularly treatment choices (Khazaal et al., 2009). It has two sections, ''reliability'' and ''quality of treatment choices.'' A final question asks the user to rate the publication overall on a three-point scale: low-moderate-high. The scale requires no specialist knowledge of the condition being researched, although it has previously been employed in content analayses of online information (Khazaal et al., 2008) and ratings of specialists have been found similar to those of laypersons when using the scale (Charnock, Shepperd, Needham & Gann, 1999). Second, the Health-related website evaluation form (HRWEF) was originally designed to evaluate websites relating to MMR vaccination (Abbott, 2000). It contains three subscales: content, authorship, and esthetics. The content subscale has been found to be the best judge of overall accuracy, but subject to higher rates of type-II error when used without the other two subscales (Abbott, 2000). These subscales control for poor design of site (esthetics) and transparency of information source (authorship). We modified the content for use on websites pertaining to pain by eliminating the final question ''webpage is pro, anti or neutral/unknown re MMR vaccine.'' The ''other features'' section of the scale was expanded to include the use of sound, interactive content, pictures or video, as previous research has indicated adolescent preferences for websites with these features (D'Auria, 2011), thus giving the scale a possible score ranging from 50 to 25. Websites were taken to be of high quality when they scored in the upper quartile of possible scores on both scales.

A further measure of the readability of the linguistic content of the sites was employed. Readability was calculated by importing text into *Google documents* where a *Flesch Reading Ease Score* (FRES) was computed. This is a score out of 100, whereby 0 is an easy to read passage and 100 is a difficult passage (Friedman & Hoffman-Goetz, 2006). This measure was chosen as it goes up to a 12th grade reading level and this was the demographic of users of interest. Five paragraphs per website were selected for an assessment of readability: (a) the first paragraph on the page, (b) the section on causes, (c) the section on symptoms, (d) the section on cures, and (e) the section on the author or organization the website was created by.

Content Analysis of Websites With a Forum Function

Seven of the 64 websites enabled an interactive posting facility. The seven websites allowed access to over 180 posts. One-hundred and sixty-four of these contained interactive posts (i.e., were added for others to see or part of a question and answer or extended exchange). A largely inductive ''bottom up'' method of thematic analysis was employed. Prior expectation of themes relating to dissatisfactory healthcare encounters, and worry about continuing pain were noted (Corcoran, et al., 2009, 2010; Seale, Ziebland, & Charteris-Black, 2006) but were not a priori searched for. All themes were developed from pattern analysis of common features, and an analysis of dominant subjects within the text. This inductive method was adopted from previously used successful internet discussion research (Coulson, 2005). All coding was done by hand by the first author, who generated a limited list of themes. The second author consulted on the veracity of the themes, in particular for their labelling. This process was repeated three times until a final number of themes were agreed upon and no further themes emerged from the data. Once this was the case the analysis could be said to have reached saturation. The themes were then reviewed for validity by a third party who was not involved in the study but who had previous experience of qualitative research on the subject of pain.

In order to ensure the anonymity and privacy of the people posting whose quotations are included in this research report, a number of protective precautions were taken. First, dates on which the websites were extracted and dates on which forum posts occurred are not listed here. Second, the URLs from which the thematic analysis was carried out are not listed anywhere in this article including in the Supplementary Table. Third, attempts were made to fragment quotations so as to be less identifiable. Lastly, quotations included in this report were entered into search engines to determine if authorship could be identified before inclusion. If quotations could be identified they were not used in the final description of the study as suggested by Rodham and Gavin (2006).

Results
Website Content

A total of 63 sites were included in the analysis, of these, 24 related to headache, 16 related to abdominal pain, and 23 related to dysmenorrhoea. Those websites coded as ''other'' were not identifiable as part of another website type and were ambiguous as to the authorship, ownership and source content. Thirty-two websites contained data on when the website was last updated. Of those which reported an update date, the average of this date was 3 years and 11 months prior to this study. The oldest website was posted online in January 1995. The youngest website was posted online in November 2010. Only two of the websites (one for dysmenorrhoea and one for abdominal pain) were written specifically for an adolescent audience. One website containing information on headache was for medical professionals and two on abdominal pain were for parents of children suffering abdominal pain. The remaining sites were not explicitly aimed at any particular type of user. Most sites were an average of three A4 pages long when printed. Fifteen pages was the maximum length of any website in this study and one the minimum length. There was no correlation between the type of pain or the type of website and length of website. As mentioned in the inclusion criteria all websites had content on possible causes of pain and possible cures or remedies. Length of this content differed greatly with some websites listing only a few sentences and other websites listing entire pages, however, there was no statistical difference between length and type of pain or type of the website. Only 40% of websites had additional features as well as text. Of these, all had a picture on their website, 11 had a video, six had sound and nine had interactive content (e.g., a game, questionnaire, or checklist).

We found that 63.9% of websites recommended seeking medical advice or gave advice on what to say to a medical professional in relation to pain. When this was assessed by type of pain 65.2% of dysmenorrhoea websites gave this recommendation, 56.3% of abdominal pain websites, and 68.2% of all headache websites gave this recommendation. There was no significant correlation between type of pain and the likelihood to recommend medical advice. A total of 37.7% of all websites recommended only pharmacological or medical treatment to cope with pain, 24.6% took a multimodal approach recommending primarily pharmacological and then another treatment and 37.7% recommended only natural remedies. No website in this study was found to recommend only behavioral pain management or only prevention.

No correlation was found between the type of pain a website focused on and the type of site, indicating that there was no bias between the types of websites focusing on this kind of information online. Of the sample studied here, only 10 of the 63 sites had a HonCode. This finding was independent of type of site or type of pain.

Website Quality Assessment

Analysis of the quality of information by type of pain was analyzed using a one-way analysis of variance (ANOVA), with type of pain (headache, abdominal pain, or dysmenorrhoea) as the independent variable. This analysis was not statistically significant for the DISCERN scale $F_{(2,59)} = 1.80$, $p = .175$, or the HRWEF $F_{(2,59)} = 2.48$, $p = .09$ indicating that quality of information did not differ depending on pain type. Analysis of the type of website (medical, media, for profit, not-for-profit, educational, forum, or other) on DISCERN scale scores was carried out using a one-way ANOVA. Significant group differences were found $F_{(5,55)} = 6.18$, $p < .001$, partial $\eta^2 = .632$. Tukey HSD tests were carried out to examine where these differences lay. Sites coded as medical type websites ($M = 64.07$ $SD = 15.11$) were found to be of a higher quality than forum sites ($M = 38.25$, $SD = 6.43$; $p = .002$). "Not for profit" sites were also found to be of a better quality than forum sites ($M = 65.00$, $SD = 15.55$; $p = .005$). In addition, medical sites were also found to be of a higher quality than "other" sites ($M = 41.23$, $SD = 19.10$; $p = .004$) and "Not for profit" sites were also higher in quality than "other" sites ($p = .011$).

Analysis of the effect of type of website on the HRWEF score used a one-way ANOVA with type of website as the independent variable. Education was excluded from the analysis as it had only one case and so comparison of means was impossible. This revealed significant group differences $F_{(5,55)} = 10.33$, $p < .001$, partial $\eta^2 = .489$. Tukey HSD post hoc tests were carried out to see where these differences lay. Medical sites ($M = 42.29$, $SD = 3.50$) were found to be of a significantly higher quality than forum sites ($M = 31.83$, $SD = 3.97$; $p < .001$) and media sites ($M = 40.75$, $SD = 7.41$) were found to be of a higher quality than forum sites ($p = .039$). "Not for profit" sites ($M = 43.33$, $SD = 4.47$) were also of a significantly higher quality than forum sites ($p < .001$). Significant differences were also found between "Not for profit" sites and "other" sites ($M = 33.50$, $SD = 5.84$), whereby "other" was of a lesser quality than medical sites ($p < .001$).

Analysis of the effect of type of website on reading ease score (FRES) was carried out using a one-way ANOVA. Significant group differences were found $F_{(5,54)} = 4.39$, $p = .004$, partial $\eta^2 = .291$. Individual group differences as calculated by Tukey HSD post hoc tests showed that forums ($M = 71.77$, $SD = 13.38$) required a lesser reading ability than medical sites ($M = 54.21$, $SD = 7.50$; $p = .005$) and "Not for profit" sites ($M = 52.24$, $SD = 15.14$; $p = .007$).

The final analysis was of the effect of pain type on FRES. This was assessed by a one-way ANOVA in which pain type was the independent variable. Significant group differences were found $F_{(2,58)} = 7.54$, $p = .002$, partial $\eta^2 = .206$, whereby sites that focused on dysmenorrhoea ($M = 65.66$, $SD = 12.61$) required a significantly greater reading ability than those on headache ($M = 52.78$, $SD = 9.50$; $p = .002$) and abdominal pain ($M = 54.37$, $SD = 13.91$; $p = .014$). The difference in reading ability required between abdominal pain and headache was nonsignificant ($p = .914$).

Content Analysis of Websites With a Forum Function

Of the 164 postings, few gave descriptive information about the person posting the message. Five posters who gave descriptive information reported themselves to be males, including one website that was started by a man wishing to seek out ways to aid his girlfriend cope with dysmenorrhoea. Thirty of the posters identified themselves as adolescents, and discussions on three forum sites were started by individuals identifying themselves as school-attending females, or of school-attending age. Two of the websites had URLs based in the UK, a third had a URL based in Australia, all others used a .com format.

Three themes emerged from inductive analysis and were labelled: passively engaged postings, actively engaged postings and reactively engaged postings.

Passively Engaged Postings

This theme is characterized by the passive consumption of information about their condition, and possible causes of action. People posted contributions that described being interested in information, but rarely did these include any request for engagement. Subthemes were labelled "coping knowledge" and "reducing isolation." In the first, posters mentioned that they were consulting with the site as they had previously no idea how to cope with the pain; they refer to previous posts and state their intention to try the forum suggestions. It appeared that reading forum content as a means of informing their coping strategies was sufficient. The second subtheme was reflected in the many postings that expressed a benefit from observing others' suffering, the validating effects of others experiencing similar problems, and the comfort in recognition of not being alone. Interestingly, these posts were often closed expressions of appreciation for the reassurance the forum offered; the absence of a question component to these posts again suggested that the participants were not attempting to elicit further responses. Frequently expressed was the sentiment that the existence of a site describing painful experience

was sufficient to momentarily alleviate negative affect. An exemplar posting was "Its horrible when you feel like crap and your the only [sic] that goes through it and then this site pops up…" (Website number 5).

Actively Engaged Postings

This theme is characterized by active interaction within a website forum aimed at generating responses from other forum members. Typically, these posts took the form of specific questions requesting solutions. This theme appeared less frequently than the first and it appears likely, based on previous research in this area that this is because only a small number of participants posting will check the forum on a regular basis (van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008). Subthemes were labelled "social support," "seeking advice," and "expressing frustration." Typically, people provided supportive statements to previous posts in order to elicit returned social support from others on the forum. An exemplar is: "hello, Ive been reading every1's messages about the period pain they get… and it makes me feel so much better… im not alone… wish I knew what was going on with my body but I am seeing the doctor tomoz [sic]….if any1 can relate I would love to hear from you." (Website number 3).

The second subtheme "advice seeking" was reflected in the many postings simply asking for help, ranging from the general to the specific. Often these were points or questions that were novel, and many were unique to the woman's experience of pain. Exemplars are: "The only thing I cant seem to get rid of is tender breasts… If anyone has any advice… that'd be great!" (Website number 1) and "I have tried all of the things people have mentioned above, but none of them really work on me. I'm only 14 years old, could something be wrong with me?" (Website number 3).

The final subtheme was "expressing frustration," as many postings were complaints about pain and pain exacerbating events, situations, or people. Typical examples included stressful school or work, unsympathetic peers or family members, and/or a lack of support from medical professionals. Emotional expression appears to be conducted with a view to both sympathising with others on the forum and eliciting a sympathetic response from others. An exemplar is "now the pain is excruciating and similar to all of you poor ladies" (Website number 5).

Reactively Engaged Postings

The third main theme is characterized by emotional responses to others' postings that stimulate variously approbation, criticism, frustration, or incredulity. These posts were the least common of all the postings and appear to be written by frequent, active users. Their use by posters was specifically to air evaluative judgements of others in the forums. Judgements, normally negative, were often made about a personal narrative posted by someone using the site to share their experience. Subthemes were labelled "narrative judgements" and "social judgements." Typically, comments revolved around a person's right to claim suffering. An exemplar posting is: "You're kidding me right? You obviously don't have the type of pain that others on this board do…." (Website number 5). Social judgements were often made about pain management practices considered socially unacceptable in some cultures, such as masturbation, or asking men for help. An exemplar posting is: "… honestly that weirdo that masturbates while she bleeds really needs to be voted off the island!" (Website number 9).

Discussion

A mixed-methods approach was adopted to investigate the content of internet sites promoting themselves as offering information and/or support to people in pain. In summary, first, a description of the content of the sites showed that most sites were medical, not-for-profit or other in terms of their website type. Only one website came from an educational source (http://www.shsu.edu/~counsel/hs/headaches.html). Websites taking a general approach in terms of who their target patient group was were common; websites designed and targeted specifically for adolescents were rare. This may be due in part to the way adolescents helped shape the search, as the adolescents we asked appear to be consumers of general rather than age-specific sites.

Second, the quality of the websites was analysed and findings showed a multimodal approach to treatment which took account of medical, pharmacological, and "natural" treatments was rare. Strategies for pain prevention were rarely employed. Websites of a higher quality were authored by medical professionals working either for medical websites or charities; websites from other sources were shorter, less detailed and of lower quality. A shorter website may not be a limitation, however, as they were authored for adolescents, who have been shown to read only some of the information presented (Hansen, Derry, Resnick, & Richardson, 2003); brevity along with readability is therefore a desirable trait in an adolescent friendly website.

Third, a more in depth thematic analysis was undertaken of the content of a subset of sites that offered a "posting" facility. This demonstrated three main methods

of interaction and use. First, the sites were used to passively receive information, second, they were used as a form of social sharing of information and support, and finally they were used to express social acceptability judgements about the appropriateness of pain management methods.

Three issues deserve further consideration. First, the quality of information in terms of its accuracy, relevance, and expert provenance, was relatively poor. Sites run by healthcare organizations and patient charities were of significantly higher quality than those run by the media or other unidentifiable sources. However, although these websites were of a higher quality they were significantly less readable making them inaccessible to many adolescents of a younger reading age. Authors of this type of information should be mindful of their target audience and attempt to simplify the language they use in order not to marginalise those with a lesser reading ability.

Second, it is interesting that websites were dominated by information content related to what to do when you are currently in pain. Content on prevention of pain was rare, perhaps reflecting that pain coping, rather than prevention, is most commonly searched for online. Nonetheless, in the websites we assessed, we perceive a gap in the promotion of self-management techniques and in clear descriptions of what could be considered red flags for potentially serious medical problems that require an urgent consultation. Young people are clearly in need of information, as supported by the thematic analysis, in which the majority of the postings were simple expressions of gratitude for information, or sharing of experience.

Third, in line with previous studies on the disinhibiting and socially distancing effects of internet communication (Moreno, Parks, & Richardson, 2007); the ''posting'' facility saw content relating only to dysmenorrhoea. Open conversation about menstruation in many societies is considered taboo, including dysmenorrhoea (Eryilmaz & Ozdemir, 2009). Coupled with the fact that pain of gynaecological origin may be stigmatizing, and adolescents find menstruation confusing and difficult (Dorn, 2009), it is perhaps unsurprising that the Internet is considered to be a socially ''safe'' environment to seek information or support. In this study, however, we found that far from being ''a value free'' environment, paradoxically others were equally disinhibited from posting extreme negative judgements against some pain management practices.

While it is beyond the scope of this study to develop a comprehensive list of recommendations that constitute a high quality website, those providing information online to adolescents in pain should be mindful of a number of findings of this research. There is a paucity of high quality,

balanced online information consistent with adolescent needs. An adolescent friendly website should contain interactive features, videos, and pictures in order to draw an adolescent's attention (D'Auria, 2011). Websites should endeavour to present written information clearly, concisely, and in simple language. Online pain forums should be moderated to limit negative judgements some users may express. Websites should also be explicit as to authorship so that consumers can determine the provenance and judge trustworthiness of content.

This research highlights the ethical implications of both online information and research. Presently, there are no standardized ethical guidelines on conducting and reporting online qualitative research. As technology advancements lead to an evolution in how we socialise and source information, the way we research this behavior must also evolve. Updating ethical considerations for research online is an urgent necessity. Ess and the association of internet researchers ethics working committee (2002) postulates that as forums are publically accessible and considered of low risk of harm, naturalistic quotations can be ethically reported. However, Seale et al. (2006) also analyzed publically accessible forums and avoided reporting quotations to prevent author traceability. The dilemma of how the anonymity of forum posters can be protected whilst providing suitable evidence to support conclusions typifies the methodological uncertainty currently facing researchers utilising the internet. One possible solution suggested by Rodham and Gavin (2006) and used in this study, is to report quotations only if the author cannot be traced if the verbatim quoted were to be entered in a search engine. Future work must develop detailed ethical guidance for standardisation of online research.

Three areas of future investigation could be profitably pursued. First, we need to understand from users directly how they experience the websites. We have no information on whether adolescents find the information credible, how it informs their pain management practice, and whether internet use augments or replaces other coping methods (e.g., family conversation, peer support, etc.). Second, a more in-depth analysis is warranted on the longitudinal use of websites, in particular those with interactive content such as message boards and ''chat'' facilities. More formal linguistic analysis would be helpful to identify how self-management ideas develop, grow, or are extinguished over time and interaction. This study was limited by our search which only retrieved menstrual pain forums and so we can only comment on those forums which focus on this type of pain. There were preliminary indications that some participants preferred a conversational or interactive style of postings in which a thread was developed and stored

with a range of advice in a ''pain narrative'' which may not be the case for other types of pain. Third, it is clear that the Internet in its current form is experienced by many adolescents as a disinhibiting form of communication. Children will share private information, including healthcare concerns, online. And although privacy issues relating to the Internet are frequently of social concern (Podichetty & Penn, 2004), it may be possible to find a public health benefit in this platform. Where social stigma and taboo lead to chronic non-disclosure of health information, treatable symptoms go unaddressed, and psychological problems of anxiety and negative self-appraisal can flourish. If adolescents are sharing such information online, it may be possible for health-care organizations to identify clinical red-flags in postings and give evidence based advice and de-stigmatizing encouragement to seek formal medical help were appropriate, or allay fears of uniqueness and difference in pain experience. Parallels could be drawn between research on pain and research into other potentially socially stigmatising conditions such as HIV$^+$ status and severe mental illness (Suzuki & Calzo, 2004).

The study has some limitations. We were limited to web content published in English and searches were run from UK servers. In addition, these findings are time specific, by the very nature of search engine mechanics, replication of this search may generate a different selection of websites. Given the open nature of the Internet, we were unable to confirm the veracity of any comments made, or the biographical details of those using sites. Further, we were unable to sample the experience of particpants who access websites with a forum but who only observe and do not contribute: their experience is likely to be different (van Uden-Kraan et al., 2008). Cultural factors were not included in the present study but are acknowledged as potentially mediators of the impact of online content (Stinson et al., 2011). Finally, because no measures existed specifically for use in pain we employed and adapted measures used in similar studies (Abbott, 2000; Charnock et al., 1999; Khazaal et al., 2008; Peterlin et al., 2008).

Many of today's adolescents are digital natives (Gray, Klein, Noyce, Sesselberg & Cantrill, 2005). The internet has always been part of their lives, for entertainment, information, learning and communication. It should be expected that young people will go online to learn about pain and pain management. When they do, what they will find will be of highly variable but largely poor quality, difficult to read, and of questionable value. The internet can provide either social support or further stigmatisation. There is significant opportunity for the development of supportive, evidence based advice, and for using the interactive features of the internet to develop resources designed to promote self-management of pain (Eccleston, 2011; Keogh, Rosser, & Eccleston, 2010); however, the internet also poses new ethical considerations that must be addressed.

Supplementary data

Supplementary data can be found at: http://www.jpepsy .oxfordjournals.org/.

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References

Abbott, V. (2000). Web page quality: Can we measure it and what do we find? A report of exploratory findings. *Journal of Public Health, 22*(2), 191–197.

Boyer, C., Selby, M., Scherrer, J. R., & Appel, R. D. (1998). The health on the net code of conduct for medical and health websites. *Computers in Biology and Medicine, 28*(5), 603–610.

Chambers, C., Reid, G., McGrath, P., & Finley, G. (1997). Self-administration of over-the-counter medication for pain among adolescents. *Archives of Pediatrics and Adolescent Medicine, 151*(5), 449–455.

Charnock, D., Shepperd, S., Needham, G., & Gann, R. (1999). DISCERN: An instrument for judging the quality of written consumer health information on treatment choices. *British Medical Journal, 53*(2), 105–111.

Corcoran, T., Haigh, F., Seabrook, A., & Schug, S. (2009). The quality of internet-sourced information for patients with chronic pain is poor. *The Clinical Journal of Pain, 25*(7), 617–623.

Corcoran, T., Haigh, F., Seabrook, A., & Schug, S. (2010). A survey of patients' use of the internet for chronic pain-related information. *Pain Medicine, 11*(4), 512–517.

Crombez, G., Eccleston, C., Damme, S. V., Vlaeyen, J., & Karoly, P. (2011). *The fear avoidance model of chronic pain: The next generation.* Manuscript submitted for publication.

Coulson, N. S. (2005). Receiving social support online: An analysis of a computer-mediated support group

for individuals living with irritable bowel syndrome. *CyberPsychology & Behavior, 8*(6), 580–584.

D'Auria, J. P. (2011). Health web sites for teens. *Journal of Pediatric Health Care, 25*(2), e1–e5.

Davis, A. R., & Westhoff, C. L. (2001). Primary dysmen-orrhea in adolescent girls and treatment with oral contraceptives. *Journal of Pediatric and Adolescent Gynecology, 14*(1), 3–8.

Dorn, L. D. (2009). Menstrual symptoms in adolescent girls: Association with smoking, depressive symptoms and anxiety. *Journal of Adolescent Health, 44*(3), 237–243.

Eccleston, C. (2011). Can 'ehealth' technology deliver on its promise of pain management for all? *Pain, 152*(8), 1701–1702.

Ess, C.; AoIR Ethics Working Committee. (2002). *Ethical decision-making and Internet research: Recommendations from the aoir ethics working committee.* Retrieved from www.aoir.org/reports/ethics.pdf

Eryilmaz, G., & Ozdemir, F. (2009). Evaluation of men-strual pain management approaches by Northeastern Anatolian adolescents. *Pain Management Nursing, 10*(1), 40–47.

Friedman, D., & Hoffman-Goetz, L. (2006). A systematic review of readability and comprehension instruments used for print and web-based cancer information. *Health Education & Behavior, 33*(3), 352–373.

Gray, N., Klein, J., Noyce, P., Sesselberg, T., & Cantrill, J. (2005). Health information-seeking behaviour in adolescence: The place of the internet. *Social Science & Medicine, 60*(7), 1467–1478.

Hansen, D. L., Derry, H. A., Resnick, P. J., & Richardson, C. R. (2003). Adolescents searching for health information on the Internet: An observational study. *Journal of Medical Internet Research, 5*(4), e25.

Keogh, E., Rosser, B. A., & Eccleston, C. (2010). e-Health and chronic pain management: Current status and developments. *Pain, 151*(1), 18–21.

Khazaal, Y., Chatton, A., Cochand, S., Coquard, O., Fernandez, S., Khan, R., . . . Zullino, D. (2009). Brief DISCERN, six questions for the evalua-tion of evidence-based content of health-related websites. *Patient Education and Counseling, 77*(1), 33–37.

Khazaal, Y., Chatton, A., Cochand, S., & Zullino, D. (2008). Quality of web-based information on cocaine addiction. *Patient Education and Counseling, 72*(2), 336–341.

Long, A., & Palermo, T. (2009). Brief report: Web-based management of adolescent chronic

pain: Development and usability testing of an online family cognitive behavioral therapy program. *Journal of Pediatric Psychology, 34*(5), 511–516.

Moreno, M., Parks, M., & Richardson, L. (2007). What are adolescents showing the world about their health risk behaviors on myspace? *Medscape General Medicine, 9*(4), 9.

Nielson (2010). Nielson Reports February 2010 U.S. Search Rankings. *Nielsen Wire, Retrieved from http://blog.nielsen.com/nielsenwire/online_mobile/nielsen-reports-february-2010-u-s-search-rankings/*

Perquin, C., Hazebroek-Kampschreur, A., Hunfeld, J., Bohnen, A., van Suijlekom-Smit, L., Passchier, J., & van der Wouden, J. (2000). Pain in children and ad-olescents: A common experience. *Pain, 87*(1), 51–58.

Peterlin, B., Gambini-Suarez, E., Lidicker, J., & Levin, M. (2008). An analysis of cluster headache information provided on internet websites. *Headache: The Journal of Head and Face Pain, 48*(3), 378–384.

Podichetty, V., & Penn, D. (2004). The progressive roles of electronic medicine: Benefits, concerns, and costs. *The American Journal of The Medical Sciences, 328*(2), 94–99.

Rapkin, A. J., & Mikacich, J. A. (2008). Premenstrual syndrome and premenstrual dysphoric disorder in adolescents. *Current Opinion in Obstetrics and Gynecology, 20*(5), 455–463.

Reid, G., Gilbert, C., & McGrath, P. (1998). The pain coping questionnaire: Preliminary validation. *Pain, 76*(1–2), 83–96.

Ritterband, L., & Palermo, T. (2009). Introduction to the special issue: eHealth in pediatric psychology. *Journal of Pediatric Psychology, 34*(5), 453–456.

Rodham, K., & Gavin, J. (2006). The ethics of using the internet to collect qualitative research data. *Research Ethics Review, 2*(3), 83–116.

Seale, C., Ziebland, S., & Charteris-Black, J. (2006). Gender, cancer experience and internet use: A com-parative keyword analysis of interviews and online cancer support groups. *Social Science & Medicine, 62*(10), 2577–2590.

Silberg, W., Lundberg, G., & Musacchio, R. (1997). Assessing, controlling, and assuring the quality of medical information on the Internet: Caveant lector et viewor–Let the reader and viewer beware. *JAMA, 277*(15), 1244–1245.

Stinson, J. N., White, M., Breakey, V., Chong, A. L., Mak, I., Low, K. K., & Low, A. K. (2011). Perspectives on quality and content of information

on the Internet for adolescents with cancer. *Pediatric Blood & Cancer, 57*, 97–104.

Suzuki, L. K., & Calzo, J. P. (2004). The search for peer advice in cyberspace: An examination of online teen bulletin boards about health and sexuality. *Journal of Applied Developmental Psychology, 25*(6), 685–698.

van Uden-Kraan, C. F., Drossaert, C. H. C., Taal, E., Seydel, E. R., & van de Laar, M. A. F. J. (2008). Self-reported differences in empowerment between lurkers and posters in online patient support groups. *Journal of Medical Internet Research, 10*(2), e18.