Case Study: Ethical Guidance for Pediatric e-health Research Using Examples From Pain Research With Adolescents

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Objective The Internet is a frequently used platform for research in pediatric and health psychology. However, there is little pragmatic guidance as to ethical best practice of this research. The absence of guidance is particularly prominent for online research with children. Our objective is to outline ethical issues in e-health research with children and adolescents using two exemplar studies in pediatric pain research.

Methods The first study is an asynchronous message board discussion amongst teenagers with pain who are frequent internet users. The second study is a web-based behavioral intervention for the management of adolescent pain.

Results Each exemplar study is discussed in the context of specific ethical considerations related to recruitment, informed consent and debriefing, privacy and confidentiality, and participant safety. Ethical issues regarding the evaluation of online psychological interventions are also discussed.

Conclusions Guidance on optimal ethical practice in e-health research is summarized.

Key words e-health; ethical issues; online research methods; pain; pediatric; qualitative methods; randomized controlled trial; research design and methodology.

Ethical Guidance for Pediatric e-Health Research Using Examples From Pain Research With Adolescents

E-health and e-technology are fast-growing research areas within health and pediatric psychology. Psychological research about pain, for example, has been delivered on mobile phone applications (Rosser & Eccleston, 2011), websites (Stinson, Wilson, Gill, Yamada, & Holt, 2009), and mobile technologies, such as tablet devices. Telecare and telemedicine advances are numerous and fast-changing, making them exciting, but difficult to track. However, legislation to encourage the ethical use of these technologies in social and psychological research is comparatively slow to keep pace with the innovations taking place in research methods and applications. This lag persists despite numerous attempts by professional organizations, such as the American Psychological Society (Kraut et al., 2004), the Association of Internet Researchers (Ess & AoIR Ethics Working Committee, 2002), and the British Psychological Society (British Psychological Society, 2007) to develop working ethics policies for e-health research. Pragmatic guidance on ethical issues for consideration and action in the design, practice, and reporting of e-health research is difficult to find. A challenge exists for researchers engaged in online psychological research to develop an ethical framework based on best practice in traditional face-to-face research methods, and experiences from early adopters of e-health research.

The primary aim of this manuscript is to address a gap in the literature by providing ethical guidance for psychologists engaged in pediatric e-health research. Ethical issues regarding recruitment, informed consent, debriefing,
privacy and confidentiality, participant safety, the delivery of psychological interventions online, and the reporting of online research will be discussed in the context of two exemplar studies: (1) an asynchronous focus group hosted on an online message board about how adolescents search for information and support about pain, called Let’s Chat Pain and (2) an internet intervention designed to teach cognitive and behavioral pain management strategies to adolescents with chronic pain and their parents, called Web-MAP. We chose these studies because a concurrent challenge in both cases was to establish, with no clear precedent, appropriate website design and research methods that support ethical approaches to recruitment, informed consent, debriefing, privacy and confidentiality, participant safety, and the delivery of psychological interventions online. Although both exemplar studies are focused on pediatric pain populations, the ethical issues raised in each case are not unique to pediatric pain and are likely to be encountered in e-health research with any pediatric population.

Description of Studies

Study 1
Let’s Chat Pain
Let’s Chat Pain is an asynchronous focus group hosted on an online message board aimed at exploring the motivational factors and coping responses of adolescents who frequently use the Internet for information and support around their health, particularly pain. Message boards can be defined as an online conversation started by one person on a webpage; this post is then viewed and a series of replies posted back by other users, generating an asynchronous discussion (Fox, Morris, & Rumsey, 2007). The message board website was created using the FluxBB v 1.4.7 tool and hosted on the University of Bath servers. Six teenage message boards discussing a variety of pain conditions were identified by the lead researcher [EH] of the Let’s Chat Pain study as platforms for recruiting adolescents. Moderators of the message boards were contacted by the researcher and told about the research. They were then asked to invite their members to participate in Let’s Chat Pain either by sending out a mass email or notification, or allowing the researcher to post a mass email or notification. Interested adolescents were given a link to the message board hosting the Let’s Chat Pain focus group and then asked to log in and give the email address of a parent who could consent to their participation. They were then led to a series of asynchronous discussions around the research topic. The lead author acted as moderator of the message board.

Study 2
Web-MAP
The second exemplar study, Web-based Management of Adolescent Pain (Web-MAP), is a cognitive behavioral therapy intervention delivered over the Internet. It has been investigated in three randomized control trials, one published (Palermo, Wilson, Peters, Lewandowski, & Somhegyi, 2009) and two on-going. The design of the website incorporates a travel theme (resembling a world map) with eight destinations, each of which is visited to learn different cognitive and behavioral pain management skills (e.g., relaxation skills, cognitive skills) using interactive and multi-media components. Different versions of the site are accessed by parents and adolescents (for a full description of content, see Palermo et al., 2009). Web-MAP is primarily self-guided with support from an online coach. The coach reviews weekly assignments completed by adolescents and parents, providing therapeutic suggestions and encouraging use of skills learned in the program. The program is designed to be completed in 8–10 weeks, with approximately 8–9 hours of treatment time per family, split evenly between children and their parents.

Rationale for Exemplar Choice
Both Web-MAP and Let’s Chat Pain are examples of online research in progress, which present us with the opportunity to comment on research methodology in this developing field. Although both studies focus on adolescents with pain complaints, we believe that the challenges experienced while conducting these two research studies will be common in online research in other pediatric populations. The population of adolescents, which is the focus of our research, is particularly salient because adolescents are described as digital natives (Palfrey & Gasser, 2008). Their engagement with technology, particularly internet technology is unparalleled both in terms of everyday usage and understanding of how these technologies work, compared with adult counterparts. The Internet is becoming an increasingly common tool for qualitative research and the delivery of online interventions. As in most pediatric e-health research, both studies presented here faced ethical dilemmas surrounding best practice for recruitment, consent, debriefing, participant safety, confidentiality, the conduct and delivery of online interventions, and the reporting of online research with children. Discussion of solutions to these dilemmas provides opportunities for knowledge transfer, with potential use of these and other strategies by other pediatric investigators.
Recruitment

Recruitment to psychological studies through the Internet has been achieved with varied methods. Similar to off-line studies, one approach is to recruit participants from the community by posting flyers in public locations (e.g., libraries, community centers), online publicly available message boards, or via study recruitment websites hosted by the researcher’s hospital or university. Ethical concerns regarding the type of recruitment strategy used in online research centres primarily on confirmation of participant identities because the researcher may never have a face-to-face encounter with research participants. This is of particular concern in pediatric research that requires parent consent for participation.

One approach to the problem of confirming participant identities is to use a gatekeeper in the recruitment process. The ethical implications of the use of gatekeepers in e-health research are similar to pediatric psychological research conducted offline (Briggs-Gowan, Horwitz, Schwab-Stone, Leventhal, & Leaf, 2000). In Web-MAP, for example, the gatekeepers to participant recruitment are health care providers, which allow the research team to confirm the identities of recruited participants, and to corroborate other information (e.g., child age, gender, etc.). The use of gatekeepers can raise additional ethical concerns, however, particularly regarding coercion. In Web-MAP, concerns about coercion are addressed by using health care providers for referrals only; all other study procedures are conducted by the research team via email and telephone. In addition, participants are informed during their participation that it is entirely voluntary and will not impact their relationship with their local health care provider. Furthermore, health care providers do not receive monetary incentives for making referrals. Similar recommendations apply when recruiting from community-based settings, such as schools or other organizations where coercion to enroll in the study is of concern. Researchers need to be mindful of their choice of gatekeepers in e-health research and implement best practice procedures to address any potential influence gatekeepers may have on participant freedom to participate or withdraw from the study.

The Let’s Chat Pain study used a novel recruitment strategy, which involved contacting the moderators of pre-existing message boards who then sent emails to all their members informing them of the study and asking them to participate. This type of recruitment is new to internet research and presents ethical challenges. Frequent users of message boards may feel more obligated to participate because of demand effects. Paradoxically, previous studies indicate that gatekeepers who send circularary emails, such as those used in Let’s Chat Pain, may recruit those members of their message board who are less frequent contributors (van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008), thereby potentially overriding the opinions of those who are the target population of the investigation.

Further ethical issues are raised with the use of monetary incentives for research participation because incentivized recruitment may be as common in e-health research (Goritz, 2004) as it is in off-line research. In Web-MAP, participant incentives are tied to completion of study assessments only and are not related to initial enrollment in the study or use of the web program. Incentive rates are similar to those used in face-to-face pediatric psychology intervention studies and were approved by the local IRB. As in face-to-face research, investigators should consider the socioeconomic status of the target population and take steps to avoid potential coercion of participants into internet studies by offering excessive financial incentives.

Once a participant is recruited into a study, barriers to research participation often arise from constraints on study enrollment, such as requirements related to language fluency, level or extent of education, and economic factors. The Web-MAP trial, for example, requires participants to speak and read fluent English, to be computer literate, and have access to the Internet. The extent to which barriers to research participation actually constitutes an ethical problem should be debated and will likely vary by case. However, there will be clear ethical issues pertaining to access to technology and the Internet, which are universal to this research area. Steps should be taken to ensure minimal exclusion of participants on the basis of technology, particularly for randomized controlled trials for treatment.

Informed Consent and Debriefing

Informed Consent

It is a requirement that researchers obtain parental consent and child assent when including adolescents in psychological research (American Psychological Association, 2010). Consent is often problematic to obtain when recruiting children to online research through websites or other online portals without the opportunity to meet face-to-face (Fox et al., 2007) as in both exemplar studies here.

In an ongoing randomized trial of Web-MAP involving recruitment of participants from across the United States and Canada, several procedures to address ethical considerations around the online consent process have been
implemented. Providers from 12 collaborating pediatric pain management centres are asked to identify potential participants during clinic visits and to secure permission to transmit participant contact details via a study website to the trial manager. On referral, the research team contacts the child’s caregiver(s) by telephone to provide a brief description of the study and conduct eligibility screening. Eligible families are sent an email with a link to view consent, assent, and HIPAA authorization forms on a secure website. In line with a waiver of written documentation from the Institutional Review Board of the study institution, which acted as the parent ethics board, consent is obtained from children and their parents over the telephone. Researchers speak with children and parents separately and use a back questioning technique, which involves asking a series of standardized questions about the consent/assent form to ensure that all participants have read the consent documents and understand the study procedures, risks, and benefits (e.g., “Can you tell me what this study is about?” “What will you be required to do during this study?” “What are the risks of participating in this study?”). Participants can then access the consent documents at any time on the study website. Parents and children who consent to participate are given separate and unique logins to the secure intervention website.

In the Let’s Chat Pain study, participants and their parents consent via email, a common approach to obtaining consent in internet research (Fox et al., 2007). However, this method presents several potential problems. First, email consent has been criticized as easily ignorable by participants when used in research (Battles, 2010; Ess & AoIR Ethics Working Committee, 2002) but may be subject to similar to constraints as paper consent (Adair, Dushenko, & Lindsay, 1985). Furthermore, the use of email means that researchers must trust that those giving consent are who they say they are (Zhang, 1999). Researchers are also not able to confirm that participants have an adequate understanding of the study procedures through email alone. Although the ethics committee of the University of Bath debated this possibility for the Let’s Chat Pain Study, it was decided that risks associated with email consent were similar to the risk of a nonparent signing a consent form in a postal survey (Fox et al., 2007).

These two exemplar studies used contrasting methods of obtaining informed consent (email versus phone). One advantage of a telephone method, as in the Web MAP study, is that participant identities could be confirmed by the referring health care provider and the parent. Furthermore, conducting consent over the telephone allows for the use of back-questioning to ensure that participants are sufficiently informed when they consent to participate in the study.

Debriefing

Many researchers choose to send an e-mail or to use a pop-up tool to provide debriefing information at the completion of the study or of the individuals’ participation (Fox et al., 2007). In Let’s Chat Pain, following their participation, all adolescents were sent the details of a number of organizations they could seek help from if distressed in any way after participating in the study. “Debriefing” methods such as this have been criticized as easily ignorable by participants (Battles, 2010; Ess & AoIR Ethics Working Committee, 2002). However, even in face-to-face research, participants may pay only cursory attention to “debrief” forms (Adair et al., 1985). As in face-to-face research, attempts should be made to ensure that all participants, even those who withdraw from the study, are fully and adequately “debriefed” and offered appropriate referral in the event of significant distress. Best practice in e-health research should involve the use of multiple “debrief” methods (e.g., email, pop-up “debrief,” telephone contact), preferably in a format that allows participants to ask questions and provide feedback to the researcher.

Privacy and Confidentiality

Privacy is defined as the control by an individual over how their private information is used, manipulated, and disseminated (Gutwirth, 2002). Psychologists practice the maintenance of the privacy of research participants by ensuring the confidentiality of individuals’ identifying information and the secure storage of all data. The violation of research participants’ privacy and anonymity through errors in data protection can have serious consequences for the personal lives of the participants, and can damage the reputation of psychology as a discipline (e.g. Humphreys, 1970). This issue is of particular relevance to e-health research, where data transmitted via the Internet and stored in remote servers can be easily compromised. As a result, some have suggested that a participant’s right to privacy and anonymity in an online research context cannot be subject to the same rules and regulations, as offline research and expectations should not be the same (Battles, 2010).

Nonetheless, researchers have an ethical responsibility to take certain safeguards to protect participant data in e-health research.

In the two studies presented here, participant privacy and confidentiality were addressed through the use of password-protected websites hosted on secure servers.
Best practice in e-health research is to follow a conservative approach by hosting websites on secure servers, using data encryption, and implementing password protection. Researchers need to be aware of the “sticky” nature of any data posted online (see Gutwirth, 2002 for an expanded discussion). Control over what data can be found when key terms are entered into a search engine, and control over upload and download of data, can only be guaranteed when using secure servers with websites hosted in one place only.

As in face-to-face research, participant privacy and confidentiality can also be protected by de-identification of data. In Let’s Chat Pain, the message board rules specified that participants should not reveal their name, geographical location, or any other identifying information, and that a moderator would delete any posts containing such information. In Web-MAP, participant responses were not accessible to anyone outside of the research team. Therefore, participant data were de-identified after data collection, as with face-to-face research.

**Participant Safety**

Protecting participants from harm is central to the code of conduct of research and human rights organizations (e.g., American Psychological Association, 2010; United Nations, 1948; World Health Organisation, 2000; World Medical Association, 2008). It remains to be seen if the potential for harm with online research is the same as using traditional face-to-face research methods. Some researchers have argued that online methods offer a limited form of communication in which nonverbal information is largely missing (Fox et al., 2000). Nonverbal communication is an important part of the richness of communication from which researchers can determine emotional states. Online, participants can easily, and without warning, withdraw from the research process (D’Auria, 2011) or may take a different meaning from exchanges with research staff than intended (Fox et al., 2007), of which the researcher may be unaware.

Moreover, bullying is of particular concern in e-health research that uses online focus groups hosted on message boards, as in Let’s Chat Pain. Key to participant protection from bullying is the establishment of expectations for participant behavior on the message board, strict moderation of participant comments, and removal of those who attempt to engage in bullying. In Let’s Chat Pain, the moderator enforced a series of “message board rules” about conduct on the message board. Specifically, participants were told they would be removed from the study if they behaved in a way that deliberately upset others on the message board. Incidents which may have been considered to constitute bullying were to be discussed among the researchers, and a decision was then made regarding removal of the participant. A critical incident protocol was in place to deal with participant disclosures of offline behaviors or events such as offline bullying or other negative health behaviors. Participants were informed that discussions online were confidential unless they disclosed something which indicated they or others were going to come to harm. No incidences of bullying occurred on the board.

Online communications, such as those obtained in Let’s Chat Pain, also raise concerns regarding participant safety because of potential disclosure of harmful health behaviors, suicidal ideation, harm to others, abuse, or neglect. It is important to consider whether individuals who choose to engage in internet research may be more vulnerable to these safety concerns than their offline counterparts. Previous studies have shown that frequent users of the Internet are more likely to have a lower mental health score and increased risk for suicidal ideation than nonusers (Dunlop, More, & Romer, 2011; Fox, et al., 2000). However, the Internet is populated not just by heavy users, and individuals who choose to enroll in e-health research are likely to have varying baseline levels of internet use. For example, in the Web-MAP study, participants from some rural communities in the United States reported having had an internet connection in their home for one year or less at the time of study enrollment. Similar to face-to-face research, a conservative approach to responding to concerns about participant safety is recommended.

Adolescent disclosure of safety concerns during participation in a research study evaluating an online intervention can be addressed using similar procedures as face-to-face intervention research, including a thorough assessment followed by disclosure of concerns and recommendations to caregivers. In the Web-MAP study, concerns about participant safety are addressed using standardized critical incident procedures approved by the local Institutional Review Board. For example, adolescents who report suicidal ideation are contacted by phone and administered a structured interview assessing suicidal ideation and intent. Results from this interview are shared with caregivers in accordance with mandated reporting laws. Adolescents who receive the suicide screening are provided with contact information for crisis hotlines and local sources of support, and those in imminent or severe crisis would be advised to go to their nearest emergency room to receive a psychiatric evaluation. Such imminent crises have not occurred in our current or completed research with Web-MAP.
There is little guidance as to ethical best practice regarding participant disclosure of safety concerns in studies such as Let’s Chat Pain, which are hosted on asynchronous message boards. Some researchers have argued that even if a participant chooses to disclose a harmful health behavior online over the course of discussion in research, they may have disclosed such information previously on similar message boards (Rodham & Gavin, 2006). In this case, not only are researchers not ethically or morally liable to help this individual, but to do so in the absence of a full case history, might be harmful to the participant (Waller, 2011) and could be seen as an attempt at establishing a therapeutic relationship where one should not exist (Sharkey et al., 2011).

The Let’s Chat Pain study took a conservative approach and developed critical incident procedures in consultation with the University ethics committee, an e-health researcher from the host institution who had experience with online adolescent research and the head of adolescent services in the local pain clinic. In response to disclosure of harmful health behaviors, such as underage drinking and illicit drug use, participants would be provided with a number of pre-identified help lines and local sources of support. However, more serious safety concerns (e.g., abuse, neglect, self-harm) were to be addressed by suspension of the message board followed by a meeting of the research team to discuss the incident and determine further action (e.g., alerting caregivers, filing a report with child protection services, etc.). Such incidences did not arise during the study, but considerations are critical to contemplate in advance of implementing study procedures so that decision rules can be built that allow for adequate protection of child participants.

### Delivering Psychological Interventions Online

An important ethical issue for licensed psychologists is the consideration of licensure rules in the particular state, province, or territory where the psychologist resides pertaining to the delivery of psychotherapeutic interventions using the Internet. The practice of technology in medicine broadly, and psychology specifically, is beginning to be defined and regulated by professional licensure boards (e.g., APA, 2010).

However, e-health research falls outside of the guidance developed for the provision of clinical services remotely using technology. As a result, concerns may be raised by ethics boards about delivering psychotherapeutic interventions to individuals living in multiple jurisdictions. For example, the Institutional Review Board that evaluated the Web-MAP study raised initial concerns that the research team was practicing clinical psychology outside of local jurisdictions where the researchers were licensed to practice (study participants reside throughout the United States and Canada). The distinction between using e-health technology to evaluate a psychological intervention in the context of research versus performing a clinical service within the health care professional–patient relationship, was at stake. Because e-health and telehealth do not have universally agreed on definitions, the stakeholder defines them (e.g., insurers define based on the services they are willing to reimburse). Telepsychology or telepsychiatry involves real-time interaction between providers and patients via videoconferencing, and this is the situation considered most frequently in US state laws and guidelines, such as those summarized recently by the American Psychological Association (APA). Although the APA does not have established guidelines on telehealth at this time, they presented a 50-state review of telehealth laws and rules (published in summer 2010 by the APA Practice Organization). Very few states were found to have established telehealth laws. There are state laws on practicing across state lines that would be applicable in the scenario in which a clinical psychologist wants to enter into a contractual arrangement to provide clinical services to a patient in another state using telehealth services. The APA recommends that psychologists approach each state licensing board for guidance in such situations. This is deemed important in regards to protecting the patient who would not necessarily know the applicable state licensing board, should he or she, for example, want to seek redress.

A complete void in the state laws exists, however, in considering the use of the Internet to deliver and evaluate psychological interventions in the context of research. Although a myriad of factors distinguish the research context from clinical service delivery, including the process of consent, and the scope, intent, and focus of the intervention and research, these factors may be difficult to understand by local ethics boards that rely on state laws. In the case of Web-MAP, it was important to educate the local ethics board about the scope of the study and nature of the interaction with study participants to allay any concerns that a provider–patient relationship was being established across state lines with study participants. Moreover, although ethics boards have legal and regulatory backgrounds, they may lack specific expertise in e-health research, and much of the terminology is not readily understandable. For example, in the case of Web-MAP, the support provided by the online coach was misconstrued as psychological diagnosis and treatment, in part, because the board did not understand what asynchronous
Table 1. Guidelines for Researchers Carrying Out Online Research With Children

<table>
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<tr>
<th>Area of online research</th>
<th>Ethical issues</th>
<th>Action required</th>
<th>Possible solutions</th>
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<tbody>
<tr>
<td>Online interventions</td>
<td>Recruitment</td>
<td>Verify participant identities</td>
<td>Participant identities can be verified through the use of a gatekeeper (e.g., referring health care provider), or by speaking over the phone with caregivers.</td>
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<td></td>
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<td>Avoid coercion</td>
<td>During recruitment and consent procedures, inform participants that their relationship with their hospital and their doctor will not be affected by their choice of participation. Consider participant socioeconomic status when determining incentive plans.</td>
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<tr>
<td>Informed consent and debriefing</td>
<td>Full parental consent and child assent must be sought</td>
<td>Seek consent on paper preferably. If this is not possible then over the phone or digitally from parents via email or fax (Fox et al., 2007). Back-questioning can be used to ensure participants have an adequate understanding of study procedures, risks, and benefits.</td>
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<td>Participants should be fully debriefed as to the purpose of the study</td>
<td>Use of multiple debrief methods (e.g., email, pop-up debrief and follow up via the mode in which you recruited the participant preferably in a way in which participants can ask questions of the researcher).</td>
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<tr>
<td>Privacy And confidentiality</td>
<td>Participant data should be protected</td>
<td>Use of a password protected secure website which delivers the intervention. If possible, participant identities should not be connected to program-use data.</td>
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<td>Participant safety</td>
<td>Researchers have a responsibility to ensure participant safety</td>
<td>The researcher’s responsibility to ensure participant safety should not go beyond the limitation of their role as a researcher (O’Connor, 2010). Researchers conducting online intervention studies often have limited or no case history for the participant and do not have an established patient–provider relationship. In the case of disclosure about abuse, self-harm, suicidal thoughts or behaviour which may harm others, standardized critical incident procedures should be followed. Critical incident procedures should be approved by the institutional ethics committee where the study is being carried out and should involve guidance from a child or pediatric psychologist. Assessment can be done over the phone using structured or semi-structured interviews. Referrals can include provision of contact information for crisis hotlines, as well as recommending that the participant access emergency health services if immediate intervention is needed. Results of assessments and recommendations should be shared with caregivers in accordance with mandated reporting laws.</td>
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<tr>
<td>Delivery of online psychological interventions</td>
<td>Psychology licensure would not be required in most instances to evaluate an online psychological intervention for research purposes</td>
<td>Currently, state laws in the U.S. do not exist regarding the use of the Internet to evaluate psychological interventions delivered in the context of research. Therefore, local ethics boards may have difficulty understanding differences between provision of clinical services online and evaluation of an online psychological intervention for research purposes. It is essential to work closely with local ethics boards to provide education about this distinction as well as clarification of any terminology that may be unfamiliar to ethics board staff with limited e-health expertise.</td>
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<td>As for online interventions, full parental and child assent should be sought, and participants should be fully debriefed as to the purpose of the study.</td>
<td>If the research participants are not in a geographical location where it is possible to seek face-to-face consent then researchers should seek consent over the phone or by email (e.g., Fox et al., 2007). Back-questioning can be used to ensure participants have an adequate understanding of study procedures, risks and benefits. Use of multiple debrief methods (e.g., email, pop-up debrief and follow-up via the mode in which the participant was recruited).</td>
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<td>Privacy and confidentiality</td>
<td>Researchers are required to protect the data of all research participants.</td>
<td>Researchers should be aware of the lasting or “sticky” nature of anything posted online when designing their research. To ensure the full protection of participants’ data in synchronous focus groups, these groups should only be hosted on secure servers and when possible on institutional servers so that the researchers have full control over the data access. Participant identities can be protected by enforcing “board rules” that instruct participants not to reveal their name, geographical location, or any other identifying information. Any posts that include identifying information can be deleted by a moderator.</td>
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<td>Participant safety</td>
<td>Researchers have a responsibility to ensure participant safety.</td>
<td>As the researcher is hosting the focus group they have a responsibility to ensure participant safety. This responsibility should not go beyond the limitation of the researcher’s role as a researcher (O’Connor, 2010), operating with limited or no case history for the participant. Rather they should attempt to refer participants to resources where they can access help both on and offline. In the case of disclosure about negative health behaviors (e.g., alcohol use), where possible provision of referrals should be done in full view of the whole group so that others who may not have openly admitted to the behavior but who are also engaging in it can also seek help. In the case of disclosure about abuse, self-harm, suicidal thoughts, or behaviour, which may harm others, standardized critical incident procedures should be followed. Critical incident procedures should be approved by the institutional ethics committee where the study is being carried out and should involve guidance from a practicing child or pediatric psychologist. As a first step, the focus group/message board should be suspended pending a full decision as to the most appropriate course of action.</td>
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<td>Moderation of the group discussion</td>
<td>To prevent and address cyber bullying, online asynchronous focus groups should have a moderator who enforces a clear set of “group rules,” which all participants should consent to before participation. These rules should include guidance on not disclosing their offline names, contact details or other identifying information to others in the group and an outline of unacceptable behavior (e.g., use of racial insults, bullying of participants, etc.) Participants who do not abide by these rules should be expelled from the focus group by the moderator.</td>
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communication referred to. It was important to explain that communications would not take place in real time. Given the lack of guidance from state laws regarding use of the Internet to evaluate psychological interventions, it is essential to work closely with local ethics boards and provide education about e-health research.

Discussion

The Internet is being used for a variety of e-health research objectives, many with pediatric populations. However, the ethical principles and practices of both the research and its reporting, particularly when the research participants are children, are still unclear and a matter for debate. Working groups from the APA, the British Psychological Society, and Ess & the AOIR committee have outlined policy for best practice on matters, such as recruitment, child and parent consent, and debriefing (British Psychological Society, 2007; Ess & AoIR Ethics Working Committee, 2002; Kraut et al., 2004). Broadly accepted guidance on internet research remains to be developed. A decision as to ethical best practice is normally the responsibility of the individual researchers and their institutional research ethics authority. Best practice in reporting is often a matter of negotiation between author, editor, and reviewer. Online research with children should be considered a special case for further ethical consideration because there is as yet no clear consensus on what constitutes good practice.

Table I summarizes the main issues for conduct and reporting that should be considered as we develop agreement on best practice for pediatric internet research. Potential issues for consideration are presented, and examples of how they were addressed in the two case studies are given. In addition, Table I summarizes the ethical stance presented elsewhere in the article for development in our thinking either through further methodological research, consensus building, or guideline development.

Our review of e-health research ethics has limitations. First, our examples are from pain management research. Although the content of the research is specific to pediatric pain, we believe the processes described earlier are transferable to different populations in pediatric psychology research. Second, the guidelines presented here will need to be regularly revisited as technology and the field of e-health research develop. Some areas of guidance have not been tested. In the studies reviewed to date, there were no or few events (e.g., disclosure of extreme distress, suicidal ideation, or bullying) that required the carefully planned ethical protocols to be used. Third, this guidance is written from a researcher perspective. Future studies could address participant views of the ethical processes and outcomes involved in e-health research.

Researchers typically undertake e-health investigations for the benefit of current and future children trying to influence their lives for the better. In the pursuit of understanding through research, psychologists have a primary duty not to harm participants or transgress their rights. E-health provides a new environment for research with either novel or atypical versions of known ethical questions. We encourage further debate and ultimately the provision of more extensive ethical guidance that can cope with new electronic media and health research with children and young people.

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References


