

Human-Computer Interaction, Ethics, and Biomedical Informatics

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Summary

Objectives: To provide an overview of recent work at the intersection of Biomedical Informatics, Human-Computer Interaction, and Ethics.

Methods: Search terms for Human-Computer Interaction, Biomedical Informatics, and Ethics were used to identify relevant papers published between 2017 and 2019. Relevant papers were identified through multiple methods, including database searches, manual reviews of citations, recent publications, and special collections, as well as through peer recommendations. Identified articles were reviewed and organized into broad themes.

Results: We identified relevant papers at the intersection of Biomedical Informatics, Human-Computer Interactions, and Ethics in over a dozen journals. The content of these papers was organized into three broad themes: ethical issues associated with systems in use, systems design, and responsible conduct of research.

Conclusions: The results of this overview demonstrate an active interest in exploring the ethical implications of Human-Computer Interaction concerns in Biomedical Informatics. Papers emphasizing ethical concerns associated with patient-facing tools, mobile devices, social media, privacy, inclusivity, and e-consent reflect the growing prominence of these topics in biomedical informatics research. New questions in these areas will likely continue to arise with the growth of precision medicine and citizen science.

Keywords

User-computer interface, ethics, medical informatics

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Introduction

Ethics in Human-Computer Interaction (HCI) covers a wide range of topics including: human welfare, ownership and property, privacy, freedom from bias, universal usability, trust, autonomy, informed consent, and accountability, among others [1]. Like HCI, biomedical informatics research and practice is deeply concerned with the ethical implications of technology design and use. The code of professional and ethical conduct of the American Medical Association (AMA), revised in 2018, highlights topics such as informed use and control of data by patients, security and privacy, respect for human participants in research, and awareness of social or public health implications as aspects of ethical behavior [2]. Although the scope of ethics in these fields can be broadly conceptualized as described above, certain key themes emerge as prevalent within the literature during any given time period. To provide an overview of topics at the intersection of biomedical informatics, HCI and ethics, we explored literature published in years 2017-2019.

Methods

We surveyed recent literature to provide an overview of key themes at the intersection of biomedical informatics, HCI, and ethics. We started with an examination of recent publications, which were used to identify search terms for both HCI and ethics. The

HCI search terms included “human-computer interaction” and variants along with additional terms discussing interfaces, displays, user-centered design, and virtual systems. Ethics search terms included topics such as bias, bioethics, security, confidentiality, privacy, disabilities, consent, legislation, autonomy, personhood, privacy, racism, vulnerable populations, underserved, and related variants. The HCI search terms were combined with the ethics terms in conjunctive searches, with the addition of a temporal term restricting results to papers published between January 1, 2017 and December 31, 2019 (to include electronic publications ahead of print). Additional articles were identified through manual review of recent publications in medical informatics journals, recommendations from colleagues, and review of curated collections including James Cimino’s 2019 Year-in-Review presentation at AMIA 2019 [3], the Journal of Medical Internet Research’s e-collection “Ethics, Privacy, and Legal Issues” for the years 2017 to 2019 [4], the special issue of the Journal of American Medical Informatics Association (JAMIA) on Health Informatics and Health Equity published in August-September 2019 [5], and through further manual searches and review of citations. Between October and December 2019, we engaged in an ongoing dialogue about this literature both with each other and with our informatics colleagues. Our reading of the literature combined with these dialogues led to the identification of overarching themes, which we present in the synthesis below.

Results

Three broad topics emerged from our reading of and dialogue about the last three years of work at the intersection of biomedical informatics, HCI, and ethics. These themes can be characterized as 1) Systems in Use, 2) System Design, and the overlapping but distinct topic of tools, and 3) Responsible conduct of research. Under our discussion of each of these themes, we highlight the breath of relevant literature, giving particular attention to the range of ethical considerations most prominently discussed in the literature.

1) Systems in Use

Studies of the implications of systems in use draw on experience with deployed tools to identify ethical issues generally not anticipated prior to system development or deployment. Using both quantitative and qualitative analysis methods, these studies attempt to look back at notable incidents, failures, or simply a body of experiences with a system *in situ*, in the hope of identifying issues or perspectives that might help avoid future difficulties.

Clinical Informatics

Potentially adverse impacts of poor usability of electronic health records (EHRs) continue to be a concern, particularly with respect to patient safety. Consistent with earlier efforts [6-9], examinations of patient safety reports continue to find evidence of a strong impact of usability problems on EHR safety [10, 11]. A laboratory study of two commonly-used EHRs in four health-care systems found wide variability in task completion time, required clicks, and error rates (ranging from 0% to 50% for various tasks), even though the products had been certified by accreditation authorities [12]. Overly burdensome and often inconsistent EHR documentation practices have also been discussed as a potential source of physician stress and safety risks [13-15]. Whether or not regulatory frameworks for EHRs might be sufficiently mature to address usability and safety concerns was explored by comparing the Office of the

National Coordinator's (ONC) policies for EHRs with analogous policies issued by the Federal Drug Administration (FDA) and Federal Aviation Administration (FAA). FDA and FAA policies were found to be more robust and prescriptive than those of the ONC [16]. Some observers have called for regulatory measures, including national tracking of EHR usability and safety problems, publication of design standards, development of standard usability and safety measurement scenarios [17], increased transparency in researching and sharing EHR usability and safety issues [18], and recommitment to shared responsibility in improving EHR use [19-21].

Usability difficulties in related clinical systems may influence the reliability of some of the data used to understand potential safety hazards associated with EHR use. A systematic review of 48 patient safety event reporting tools identified usability issues such as omission of input validation facilities and hierarchical data layout as frequently found shortcomings [22]. Although the authors do not speculate as to the exact nature and magnitude of the impact of these difficulties, it seems possible that usability problems might lead to inaccurate and incomplete reports, and subsequently to undercounting safety events.

Personal Health Informatics: PHRs, Portals, and Personal Health Information Management

Patient portals bring a different set of challenges, particularly since usability or interaction design shortcomings may effectively disenfranchise patients who find the tools difficult to use or even inaccessible [23]. Encouragement from providers, perceived possibilities of greater access to health information, and improved communication can facilitate portal use, while lack of awareness, lack of training, and privacy/security concerns present barriers [24], although others have noted that focusing on individual concerns might obscure systemic inequities that discourage use [25]. However, experience with the OpenNotes platform suggests that direct sharing of notes through patient portals might be beneficial. A survey of almost 30,000 Open-

Notes users from three health care systems found that patients found notes helpful for managing their health, with relatively low rates of confusion and substantial benefits among potentially vulnerable populations, including those with lower education levels and non-native English speakers [26].

Social Media and Online Communities

The majority of articles focused on ethical concerns at the intersection of social media and biomedical informatics published during the review period focus on the ethical conduct of research on and through these platforms [27-33], including consideration for particularly sensitive cases in mental health [34,35]. A few articles discuss the ethical issues associated with direct use of social media for health by patients and providers as they relate to HCI [36, 37]. Social media systems often do not clearly indicate the extent to which healthcare providers access and attend to information posted by patients on social media platforms. As a result, patients may post information that they would otherwise not want their provider to see without realizing that a provider may be able to access this information [31, 36]. Conversely, patients may post information believing that a health-care provider both has access to and will respond to the post. Both cases underscore the need for designs that clearly signal both potential and actual consumption of and responsiveness to posted information by healthcare providers and other individuals. Another key issue relates to information interpretation by patients and providers, who face challenges in interpreting comprehensiveness, accuracy, completeness, and authenticity of information posted on social media platforms [36, 37]. The presence of both missing information and misinformation generated by both individuals and automated bots emphasizes the need to design systems that use clear communication of potential risks to mitigate adverse consequences [38, 39]. The use of social media for targeted advertising, particularly for sensitive topics such as mental health services, presents additional questions as to which applications of these data are considered to be

acceptable [40]. A final concern relates to patient understanding of privacy risks as communicated by complex, evolving, and opaque terms and conditions on social media platforms [36, 39]. There is significant opportunity for deeper understanding and intervention from both the HCI and biomedical informatics communities across these areas of concern.

Mobile

Mobile health apps present several ethical concerns. Prominent among these concerns are privacy and security, particularly when personal health data is involved [41-45]. Examinations of these questions from the perspectives of specific sub-groups, such as men who have sex with men [46] or under-represented ethnic groups [47] emphasize the importance of understanding the needs of specific populations. There is also a need to consider privacy and security as it relates to unintended users. For example, bystanders of an individual using an app intended to capture illicit drug use may inadvertently, without their consent, share elements such as their location, voice, topic of conversation, and other data elements [48].

Clinical applications present similar ethical issues. Although initial data from a small survey suggests that patients might be willing to share data from their devices for use in mental health assessment [49], the use of mobile apps to directly provide psychotherapy and more general mental health support [50] raises concerns about accountability and privacy as well as the need for such systems to explicitly acknowledge the limitations of the source of advice [51]. In an echo of some of the earliest discussions of concerns over the impact of artificial intelligence [52, 53], the emergence of automated chatbot therapy apps has led to calls for ethical standards concerning privacy and the need for disclosure of the automated nature of the tools [54]. The use of mobile devices for communication of other health-related information, such as medication descriptions, have similarly raised concerns about effective communication, usability, and appropriate regulation [55].

2) Systems Design

Projects in this category differ from discussions of systems in use in that they involve development of novel systems design with the explicit goal of meeting previously unfulfilled ethical considerations. To reach this goal, these projects may be associated with qualitative up-front efforts aimed at understanding relevant needs and preferences and developing designs to account for them.

Perhaps unsurprisingly, attempts to address ethical concerns through novel designs continue to be challenged by the complexities of clinical users and contexts. Preliminary studies of an EHR system that uses pixelation to protect privacy by hiding sensitive information found the design might have improved understanding of privacy concerns. However, difficulties with the inconvenience of revealing the information and the possibility of missing important information raised concerns among potential users [56]. Similarly, a proposed privacy protection design has provided patients with facilities for redacting sensitive content from EHR documents. Although preliminary focus group evaluations found that users had appropriate mental models, several novel requirements were identified, including the need for establishment of trust and clear communication of the handling of redacted data [57].

The importance of considering the perspectives of distinct patient populations is seen in a range of efforts, including preliminary inquiries into potential designs for managing opioid abuse risk in military settings [58], teen smoking prevention tools [59], electronic system decision aids for depression [60], apps for menstrual tracking [61], personal health records for young adults leaving foster care [62], and identification of research areas for informatics support of families experiencing challenges of hospitalization and subsequent care [63]. A proposed clinical trial of the potential use of computer-delivered advice for encouraging physical activity in underserved populations [64] illustrates issues at the intersection of trust, inclusivity, and HCI, as different groups may have different responses to these automated agents. Although social media may play a role, as in a project using analysis

of blog posts to understand the sentiments and attitudes of individuals undergoing gender transitions [65], in-depth work with individuals and groups representing these diverse perspectives is likely to be critical to both successful design and responsible use of informatics tools.

3) Research Conduct

Efforts in this category focus on the development of interactive tools in the support of appropriate conduct of research activities, primarily focusing on outreach and consent to participate in research. As identifying potential participants and helping them become better-informed about the implications of their participation are key components of ethical research conduct, questions of trust and related issues of fairness are not far behind.

Consent, Trust, and Participant Engagement

Tablet, mobile, or portal-based systems present new opportunities for effectively providing educational materials necessary for informed patient and research study consent. Qualitative studies assessing user needs and preferences have suggested that these tools might effectively address user concerns and potentially increase participation among under-represented groups [66, 67]. However, evaluations have not always found clear wins, with some studies failing to see improvements associated with the use of e-consent [68], and others finding difficulties with complex content [69]. Other efforts have explored interface designs intended to slow users down in the hopes of increasing comprehension [70], and the use of learning theory to design consent content [71]. A review of research on consent processes for research mediated by mobile apps found a range of practices, including some not found in traditional consent, such as assessments of consent understanding and the use of finger-drawn signatures [72]. The broad range of delivery methods, study designs, and assessments used in these studies suggests a need for further work to better understand which approaches might work best in which contexts.

Recruiting

Informatics approaches can contribute to the reduction of bias in research studies, as seen in a study that found that patients excluded from a medical device trial due to lack of computer or internet access were among those who might have been most in need of the intervention [73]. Changes to recruiting practices might address some of the imbalances in research participation, as seen in a large trial involving the use of a patient portal to invite participation in a research recruitment registry. Portal invitations led to appropriate representation for women, but differences for Black males, Hispanics, and Asians persisted [74]. A similar approach aimed at urban African-Americans embedded recruiting information in personalized lists of health-related community resources, with encouraging preliminary results, although overall recruitment rates remained low [75]. The PRIDE study, which used in-depth efforts from advisory panels and outreach ambassadors to guide the design of a research platform for a cohort study of sexual and gender minority people [76], provides an example of how a commitment toward understanding and working with underserved or otherwise historically marginalized communities on both the explication of information needs and subsequent design responsive to such needs are critical to successful engagement in research.

Recruitment through social media is also a possibility. A survey of Twitter users and participants on a crowdsourcing platform found that most users might not object to monitoring Twitter content to find study participants, but variations in preferences suggest a need for caution [77]. Similar concerns informed the development of a privacy-by-design framework for using social-media to identify study participants [31].

Conclusions

Our reading of the last three years of scholarship at the intersection of biomedical informatics, HCI, and ethics demonstrates an active dialogue about the issues. The value placed upon such discussions is exemplified by the robust collection of articles identified

through this overview and published in over a dozen journals, including special issues on the topic in both JAMIA and the Journal of Medical Internet Research (JMIR). The three themes identified provide a useful starting point for considering the breadth of work at this intersection, namely systems in use, system design, and research conduct. The publications of the last several years emphasize the need for future scholarship particularly in mobile health and social media, inclusivity, and e-consent. As informatics applications expand into emergent domains, so too will the range of ethical considerations that the field will need to address. For example, new questions related to privacy, welfare, and inclusivity, among others, will result from the rise of precision medicine and citizen science [78]. Similarly, the rapid rise of mobile tracking as a mechanism for public health surveillance and telemedicine in the wake of the COVID-19 pandemic will necessitate additional debates at the intersection of biomedical informatics, HCI, and ethics [79, 80]. Given this dynamic landscape, there will be an ongoing need not only to engage in ethical discussions but to synthesize and present them in ways that are accessible to the biomedical informatics community.

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