

Turning to Bioethics to Inform the Design of Health Technologies

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Abstract

Bioethics is a discipline that examines ethical issues that arise in relation to healthcare. This interdisciplinary field was formed in response to advances in health technology that opened up challenging ethical questions. After presenting an overview of the field of bioethics, I describe three areas of focus in bioethics: power, consent, and cultural context. These areas are increasingly relevant to individuals at the intersection of the Human-Computer Interaction and Health Informatics. I argue for researchers to turn to bioethics to gain a nuanced understanding of these issues.

Introduction

“Many people fear that science and technology are encroaching on domains of life in a way that undermines human dignity, and they see this as a threat that needs to be resisted vigorously. They are right. There is a real crisis, and it needs our attention now, before irreparable damage is done to the fragile environment of mutually shared beliefs and attitudes on which a precious conception of human dignity does indeed depend for its existence.”

– Danielle C. Dennett, in Human Dignity and Bioethics: Essays Commissioned by President’s Council on Biomedical Ethics] (1).

As scientific breakthroughs such as genome editing occur at a breathtaking pace, a host of ethical issues arise that have yet to be dealt with. In the field of technology design for healthcare, many unresolved ethical concerns have arisen. These include unequal access to beneficial technologies by underserved groups, privacy risks posed by new technologies, and the ways that researchers may further marginalize certain groups or power inequalities through the ways that they go about research and design. The field of Bioethics has examined many of these issues and can be useful for researchers and designers studying the design of interactive health technologies.

Bioethics is concerned with ethical issues in health care, research, and policy. The field arose in response to ambivalence about the ethics of using new technologies: specifically, dialysis machines. In the 1960s, these machines were of short supply and committees had to decide which patients would receive treatment, raising immediate troubling ethical questions that needed practical responses (2). Other incredible medical advances and treatments, as well as research scandals added to the impetus for the field to form (3). Though health care practitioners had long written about ethics, the shift to an interdisciplinary group of researchers to consider ethical questions was in part motivated by a shift from a paternalistic model of care to a person-centered model which emphasizes the input, values, and preferences of the patient (3).

Answering questions in bioethics requires interdisciplinary perspectives, and the field benefits from individuals with backgrounds as diverse as theology, philosophy, law, nursing, and the social sciences (2). Topics of interest to this community shift in response to societal values and emerging technologies and scientific developments. Some areas of interest to the field include privacy, autonomy, end-of-life care, and consent (4). Bioethics has been credited for the implementation of informed consent in medical practice as well as research being overseen by Institutional Review Boards. Also in addition to the academic discipline, individuals practice bioethics by sitting on IRB boards, consulting in hospitals, and serving on commissions – one notable example being the President’s Council on Biomedical Ethics in the United States.

Drawing on the Field of Bioethics to Inform the Design of Technologies in Healthcare

An area of interest to researchers in the fields of Human-Computer Interaction as well as Health Informatics are ethical issues in the space of health technology design (e.g. (5)). As an established field that focuses on precisely the ethical issues raised by health technology researchers, Bioethics has much to contribute. Additionally, as technology plays a role in many of the new ethical decisions that health care professionals face (4), health technology researchers can contribute their expertise to the field of bioethics. There are a number of relevant areas of Bioethics, including power, privacy, dignity, and autonomy. Below I focus on the concepts of power, consent, and cultural context, and how they relate to health technology.

The field of Bioethics has traditionally been concerned with the topic of *power*, beginning with a focus on the power doctors have over patients as well as historical wrongs done by health care practitioners (e.g. those disclosed during the Nuremberg trials (6)). Another emerging area of interest to health technology researchers are discussions of how research may inadvertently further disempower vulnerable or marginalized populations (e.g. a discussion of technology design and dementia (7)). Researchers can draw on nuanced understandings of this issue in Bioethics – including critiques of how bioethicists have questioned their own use of a status as moral authority to further the interests of powerful figures and institutions and maintain the status quo (8). Finally, a movement from a paternalistic to a patient-centered model of care can be seen as a reconfiguration of power. The patient-centered movement has been embraced by health technologists, who have examined and designed platforms to support patients in collecting and analyzing their own health data, receive mentorship from peers who share a diagnosis, and manage their health care conditions. We can turn to bioethics to further understand the context and history of the patient-centered movement, as well as to consider tradeoffs involved (e.g. autonomy vs. community) and to consider populations for whom the patient-centered model may not be appropriate.

When configurations of power favor doctors, consent is less important as patients are not considered the primary decision-makers for their care. A shift towards patient-centered care involves an emphasis on *consent* for all participation in research and clinical settings. In technology design, one area of interest in regards to informed consent that has emerged recently has been understanding how to account for the persistence of health data enabled by technological systems, and secondary uses of data that are enabled. For example, researchers have examined how privacy concerns and needs of patients with diabetes shift over their lifetime, in part in response to experiences with technology (9). Conversations in Bioethics that can inform this topic include discussions of Advanced Directives. Advanced directives allow people to specify preferences for healthcare treatments (e.g. “do not resuscitate” orders) or individuals who can make decisions in the event that they are no longer able to make decisions for themselves. Bioethicists have pointed out risks of adhering to advanced directives without reserve, as there are complicating factors (e.g. treatments may advance, the reality of living with a condition may be different than imagined) (10). Understanding the ethical dimensions of attending to decisions made in advance can inform the design of technologies that utilize patient data for a prolonged period.

The field of bioethics has grappled with the different factors that affect a population’s comfort with contemporary trends in the Western healthcare system, such as the shift away from paternalism (e.g. (11)). Researchers investigating the design of health technologies are interested in reaching vulnerable and underserved communities, which often include racially and ethnically diverse populations (12). Some of these individuals may have different cultural and historical contexts than those often targeted by technology designers. Bioethicists grapple with the ways that ethics are influenced by cultural and historical contexts (e.g. Hindu Bioethics (13), Christian Bioethics(14)). Understanding the work that has been done understanding ethical issues in these very specific contexts can help researchers who work with these populations.

Conclusion

The issues identified by the field of Bioethics do not provide easy answers for technology researchers and designers. However, the field has grappled with many of the issues that technology designers in healthcare confront today. In this abstract, I describe the history of bioethics as well as three topics relevant to our field, including power, informed consent, and the importance of considering cultural context.

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