Collecting and Managing Data in Public Health Research on Autism

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Abstract

Significant efforts in the CHI community have focused on supporting autism research through intervention-based work. For example, applications of mobile systems, therapeutic games, gesture-based interaction, and capture and access have been studied in the context of therapy, care, and interventions for individuals with autism spectrum disorders. In this paper, we discuss how HCI can support population-focused strategies, or a public health approach, to autism research. Public health research is focused on collecting and managing large amounts of data at the population level in order to understand aspects of autism such as early detection, lifespan outcomes, and risk factors. We discuss a research agenda for HCI that involves opportunities for innovative multidisciplinary autism research at the population level rather than the individual level.

Author Keywords

Public health informatics; organizational information systems; computer-supported cooperative work.

ACM Classification Keywords

H.5.3. Group and Organization Interfaces: Computer-supported cooperative work; J.3 Computer Applications: Life and Medical Sciences—Health.

Introduction

The CHI community has a long history of designing and evaluating novel interactive systems in support of therapy and care for individuals with autism spectrum disorders. Individual-level research on autism investigates topics such as interventions [3, 27], home [19, 22] and school [13, 24] contexts, and quality of life [17]. This research area has generated rigorous and meaningful scholarship at CHI largely due to the rich opportunities to engage in participatory design [8], apply novel interaction paradigms [7, 26], study collaboration [23] and social skills [3], and balance multiple stakeholder needs [15].

In contrast to individual-level research, population-level research takes a broader view of autism to understand and take action on such aspects as risk factors, prevalence, outcomes, and intervention at the public policy level. Naturally, this type of research involves larger scale studies such as clinical trials or geographic analysis of health data. Studies at this scale are not always appropriate, feasible, or necessary in the context of HCI research. However, in our experiences both collaborating with, and studying the practices of, public health researchers, we have identified interesting areas for HCI research.

In this paper, we discuss the potential for the CHI community to expand its contributions to autism research through more population-focused work. We define a multidisciplinary research agenda categorized across three areas:

1. Survey data collection at scale
2. Participant recruitment and monitoring
3. Distributed collaboration and awareness

Methods

Over the past two years, our HCI research group has collaborated with a university-based autism center that takes a public health approach to research. Our multidisciplinary collaboration was initially driven by mutual interest in the development of novel technology-based interventions for autism spectrum disorders. However, the center's growth led to administrative discussions about systems and practices used to manage research data. Our expertise in HCI was sought during these discussions, and we became involved in strategic planning around the center's use of information systems.

As a result, we launched a project focused on understanding information needs within the center, exploring why existing systems were not meeting their needs, and developing innovative information systems to meet these needs. We conducted contextual inquiries with 22 members of the research staff involved in handling data, across three different areas of research. Through inductive thematic analysis, we identified pain points and opportunities by investigating information needs at the individual, group, and organizational level.

In this paper, we share a research agenda that has emerged from this project, focused on public health research on autism. Our aim is to engage the CHI community in exploring potential contributions, and encouraging more work in this area given the need we have observed. There is notable enthusiasm and momentum around this multidisciplinary project. Opportunities for both funding and publishing appear to be promising across disciplines. We continue to find new information needs, usability challenges, and design

problems to explore with an increasing number of collaborators in this space. As HCI researchers and students, we are finding a rich environment to explore our own research interests and pursue contributions of interest to the CHI community.

Survey data collection at scale

Surveys are a common method of collecting self-reported data from a representative sample of an entire population. For example, a survey of parents of children with autism may be used to elicit geographic-based data for studying environmental risk factors, or understanding the extent to which available clinical services are meeting local demand. HCI research has the potential to provide novel data collection methods, improve response rates, increase accuracy of data collected, and streamline management and analysis of large amounts of incoming data.

Web-based survey administration is increasingly used, allowing HCI researchers to contribute investigations of how online survey design affects response rates, completion rates, and data quality. Design decisions such as pagination, navigation, constraints, progress indicators, and login functionality can have important implications for successful population-based data collection. Surveys may also be completed by individuals with autism themselves, providing opportunities for studying universal design [2], inclusion in design [14], assistive technology [5, 6], and similar topic areas of interest in HCI.

Additionally, innovations on sampling methods could have significant implications for public health research. For example, paratyping [11], experience sampling [12, 18], and ecological momentary assessment [17]

are methods that have been pioneered or advanced by HCI research such as context awareness, ubiquitous and wearable computing. On the other hand, paper surveys are still commonly mailed to potential respondents, driven by public health's interest in reaching various segments of a population regardless of access to technology. Understanding, supporting, and augmenting paper-based practices [24] can help support the need for persistent use of paper surveys, which requires considerable effort in data entry.

Participant recruitment and monitoring

Multiple areas of autism research involve longitudinal studies that require recruiting large numbers of participants, keeping track of them for several years, and making contact for multiple data collection points over time. Studying biological and environmental risk factors on the incidence of autism spectrum disorders requires recruiting pregnant women to collect samples throughout fetal and neonatal development. Another significant research area is understanding how early detection and intervention (within the first three years of life) improves health outcomes and quality of life later on. A sample study on early detection will require data from 8,000 children, collected 3-4 times over the course of two years.

The challenges of recruiting, monitoring, and collecting data from participants over long periods of time pose interesting problems well suited to HCI perspectives. Coordination and monitoring across many clinical encounters over time has been recognized as a unique design challenge in HCI [23]. Related work that could be applied to the management of large numbers of patients and their data in longitudinal studies include: clinician dashboards for patient management [1], real-

time feedback displays [20], information sharing across stakeholders and caregivers [21], and novel approaches of engaging patients during and after clinical encounters [25, 28].

Data visualization techniques, which have been applied to autism interventions for individuals [9], also have potential to aid with management of large longitudinal studies. How could data visualization assist research coordinators with ensuring timely, accurate, and rigorous data collection? How could points of contact with participants, and associated incoming data streams, be visualized to help public health researchers interpret progress in data collection and make decisions about where and how to adjust efforts? How could multiple streams of incoming data be aggregated to aid in real-time analysis that could also allow for adjustment of ongoing data collection?

Account management and authentication currently pose significant barriers to participant retention. Researchers we studied reported serious problems with ensuring data security and HIPAA compliance, without compromising usability. As a result of these usability issues, they have experienced concerning levels of participant drop out, from both clinicians and parents of children with autism. This problem is suited to user-centered design approaches, and novel HCI research in account management and authentication [10].

Distributed collaboration and awareness
The large scale of population-based research also results in coordination across a variety of stakeholders, which are often not collocated. For example, multiple universities and autism centers often collaborate on a study in order to increase capacity for recruiting participants or add geographic variation. A data coordination center is commonly appointed to manage statistical analysis across study sites, and typically led by epidemiologists. We are currently involved in managing sociotechnical aspects of data coordination centers across several projects.

As discussed in the previous section, participants such as patients, caregivers, and clinicians must also be managed effectively in addition to coordination across researchers at study sites. For example, a pediatrician may be involved in providing assessment data on multiple children in their clinical practice, while these children's parents also provide self-report data using a separate interface. One parent may have multiple children involved in a study, due to interest in genetic and environmental risk factors that can be compared among siblings. Ultimately, researchers must accurately match these streams of data in order to analyze the data they have collected. Participant IDs are generally provided (*i.e.*, one per child), in addition to authentication credentials (*i.e.*, for the parent), resulting in poor usability.

We have become particularly interested in the complexities of these multiple levels of coordination, as a distributed collaboration and awareness problem [1, 25]. A portal is typically required for each stakeholder to be able to access tailored functionality for data entry and/or data review. A plethora of research in the area of computer-supported cooperative work is well aligned to these complexities. For example: How can a data coordinating center manage access to protected health data across study sites, researchers, clinicians, and parents, without sacrificing usability? How can each of these stakeholders be provided with appropriate and

usable levels of awareness about the activities of others, and their own personal status (*e.g.*, As a researcher, which children do I need to make sure we receive data on this month? As a parent, how can I be reminded that my child's data is due to researchers? As a clinician, how can my assessment data collection be imbedded into my existing workflow as seamlessly as possible?).

Conclusion

Through multidisciplinary collaboration with public health researchers focusing on autism spectrum disorders, we have identified a rich and varied research agenda for HCI research. Given the CHI community's rich history contributing to autism research at the individual level, and interesting overlap in research interests at the population level, we see potential for more work in the area of public health. In this paper, we have shared three areas of immediate research interest which we have begun exploring with our collaborators: survey data collection at scale; participant recruitment and monitoring; and distributed collaboration and awareness. We encourage consideration within the CHI community for the potential contributions in these areas across disciplines. In the future, we see additional opportunities for closer collaboration between our disciplines in other areas of shared interest, such as social computing and geographic information systems.

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