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Ethical Aspects of Health Sensing Applications in E-Textiles †

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Abstract: The role of e-textiles has been discussed widely for health sensing applications. However, the ethical aspects of health sensing e-textiles have received less attention in the literature. In this contribution, we aim to identify the ethical concerns that emerge from the collection and use of health data from e-textiles. To identify these concerns, we draw upon the literature on health wearables and m-health applications. We propose that four ethical concerns need to be accounted for in the design of e-textiles that collect health data. These are privacy, discrimination, autonomy, and harm. We discuss the need to address these ethical concerns during the design process.

Keywords: health sensing; e-textiles; ethics; surveillance

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1. Introduction

E-textiles are being widely developed for health sensing applications, such as smart health, healthy ageing, sports, fitness, and wellness [1]. Sensing technologies can be integrated within e-textiles, such as into the fabric or the yarn, to collect a wide range of health data. E-textiles can communicate with smartphones and computers to collect, display, store, and process physiological information such as heart rate, temperature, breathing, stress, movement, acceleration, or even hormone levels. The use of e-textiles in the health domain can help users monitor health conditions, treat diseases, maximize cognitive and physical function, and promote social engagement and interactions [2]. They can also be used in specialized medical settings to monitor patients' health, postures, and physiological states in real time.

In the health sensing domain, e-textiles have been argued to be the next level of technology after mobile health and wearables [3]. Mobile health (m-health) refers to mobile applications in the health domain, such as fitness apps, weight-watching apps, exercise apps, etc. [4]. Mobile applications collect data through both embedded sensors and self-logging by users. Health wearables refer to devices such as smartwatches and pedometers with sensors for capturing health-related data. The literature has discussed several ethical concerns pertaining to m-health applications and wearables, even though they are voluntarily adopted by millions of users across the globe. However, ethical aspects of e-textiles have received relatively less attention in the literature. This is potentially because e-textiles are an emerging technology that is yet to become as ubiquitous or accessible [4]. However, there is a need to anticipate potential ethical issues in advance. In this paper, we argue that the ethical concerns posed by m-health applications and wearables extend to health sensing applications of e-textiles. To identify these concerns, we draw upon the existing literature from these domains [5,6]. We identify four major ethical concerns, which are privacy, discrimination, autonomy, and harm. We show how these concerns are replicated or exacerbated in the context of e-textiles.

2. Background

Ethical concerns have been discussed widely in the domain of m-health and health wearables. It has been argued that through the use of m-health applications, users become

subjects of both surveillance and persuasion [4]. They present their body and their self as open to continual measurement and assessment. Wieczorek et al. [5] conducted a literature review of health wearables and identified areas of opportunities and concerns associated with self-tracking. Sharon [6] discussed the disciplining and disempowering effects of wearables, outlining their impact on values of autonomy, solidarity, and authenticity.

In this paper, we argue that ethical concerns pertaining to m-health and health wearables extend to the health sensing applications of e-textiles as well. Since the data collected by e-textiles are potentially more intimate, accurate, and sensitive, in many cases, these concerns might be exacerbated. However, critical literature has not emerged in this area. Therefore, there is a need to understand the ethical aspects pertaining to the design of e-textiles for health sensing applications.

3. Ethical Aspects of Health Sensing Applications in E-Textiles

In this paper, we draw upon the literature on m-health and health wearables to identify the ethical aspects of health sensing applications in e-textiles. We discuss how these concerns might operationalize in different application contexts. We discuss four ethical aspects of e-textiles: privacy, discrimination, autonomy, and harm (Figure 1).

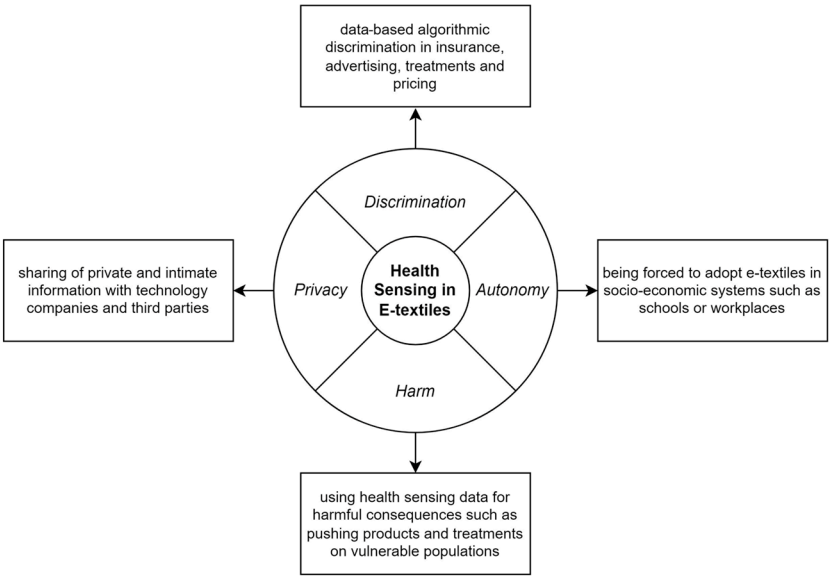


Figure 1. Ethical concerns in health sensing applications in e-textiles.

3.1. Privacy

Inarguably, the most pronounced concern that emerges for health sensing e-textiles is that of privacy [5]. Privacy has emerged as a significant concern across different types of sensing and surveillance technologies. Health sensing technologies can collect a wide range of data, from trivial to intimate. While some health wearables may collect less sensitive data such as the number of steps walked by a user, the data collected by e-textiles are more intimate by design. E-textiles may collect highly sensitive health data such as body temperature, perspiration rates, stress levels and movement patterns [1]. On one hand, these datasets may be better suited for functional purposes. On the other hand, privacy concerns are higher due to the intimate nature of the data. As users adopt e-textiles for several health and fitness purposes, they may inadvertently end up sharing sensitive private information with technology companies, service providers, and third parties.

3.2. Discrimination

The data collected from health-sensing e-textiles poses not only privacy concerns, but also concerns about data-driven discrimination. Health data collected from various sources are often processed for decision-making purposes in different industries. The more

sensitive the data are, the more they can be used for inferential decision-making purposes in areas where users least expect it or are not prepared for it. Health data collected by e-textiles can be used for decision-making in markets or in medical setups. When private data are shared with different stakeholders, users may end up being discriminated against by algorithms used in insurance, advertising, treatment, pricing, etc. [7,8]. For example, within insurance, it may so happen that users who are unaware of their own pre-existing conditions are sold insurance plans at the highest prices. Health data may also be used as a justification to discriminate in medical treatments, for example, to prioritize patients in limited-resource settings. In the domain of advertising, algorithms may exploit users' health vulnerabilities to suggest targeted products, which users are tempted to buy out of fear but do not really need.

3.3. Autonomy

Another concern that has surfaced prominently in the literature is that of autonomy. The value of autonomy is often invoked to articulate both the benefits and the concerns about health wearables [6]. Health sensing is surrounded by the empowerment narrative, promising greater self-knowledge through numbers [5]. Advertising of health wearables seeks to convince customers to gain control over their health, weight, and sleep, facilitated by troves of data. However, the empowerment narrative is accompanied by perceptions of individual responsibility. In the workplace, employers are encouraging employees to adopt wearables [9]. Insurance companies commonly offer discounts to customers who self-track [8]. In such arrangements, the line between voluntary and compulsory participation often blurs [7]. The normalization of e-textiles for health sensing and their integration within socio-economic systems may force users into involuntary participatory arrangements. Users may be forced to adopt e-textiles in schools and workplaces, akin to the current push towards wearables [9]. Another autonomy-related critique of health sensing concerns the value of authenticity. Data-driven approaches to health have been criticized in the literature as unidirectional and reductive [5,6]. It has been argued that these approaches prevent individuals from exploring alternate means of health management.

3.4. Harm

Lastly, the data collected through e-textiles may be used intentionally or unintentionally to cause harm. For example, e-textiles with sensors that detect users' stress levels may share their data with advertising companies, promoting the sale of addictive medication while a user is in their most vulnerable state. Health sensing data may be used as a justification to deny users medical treatments. E-textiles may also cause unintended harm. They may inadvertently expose users to information about underlying medical conditions without them seeking out this information. They may cause users undue mental distress with false positives about underlying medical conditions. In contrast, they may fail to detect an ongoing medical emergency, such as a heart attack, giving users a false sense of comfort even when their symptoms tell them otherwise.

4. Discussion and Conclusions

The ethical aspects highlighted in this paper apply to nearly all use cases of health-sensing e-textiles. There is a need for designers to actively mitigate these concerns. For this purpose, it is important that designers are able to anticipate these concerns in advance, during the design activity, a process termed moral imagination [10]. Moral imagination allows designers to anticipate ethical concerns using ethics frameworks such as the one presented in this paper. Designers can systematically assess whether their sensing applications violate users' privacy or autonomy, or whether they can be used to perpetuate discrimination or cause any harm. Addressal of these concerns is important to build users' trust in technology, especially when several technology products are facing a 'crisis of ethics' [11]. We believe that this contribution is a timely one to initiate a discussion on the ethical aspects of e-textiles, and foreground ethical concerns in the design activity.

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