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The Emotional Work of Doing eHealth Research

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Abstract

Within Human-Computer Interaction (HCI), researchers have become more aware of the interplay between the work they are doing and their own health and wellbeing. These issues have been discussed mostly in the context of HCI research around sensitive issues (Sensitive HCI). We argue that researcher wellbeing needs to be considered in all eHealth and mHealth research. Here, we focus on the *emotional labour* required by the political and organisational structures of eHealth research, and illustrate it with autoethnographic observations from two research studies, a trial of an eMentalHealth intervention, and an evaluation of a health insurance scheme in Tanzania. Based on a review of relevant literature from health and social care research, we suggest a process for supporting emotional work that can be adapted to other application contexts.

Author Keywords

eHealth; researcher wellbeing; emotional labour; sensitive HCI; codes of good practice; research process

ACM Classification Keywords

H.5.m [Information interfaces and presentation (e.g., HCI)]: Miscellaneous; K.7.4 [Professional Ethics]: Codes of Good Practice; J.3 [Life and Medical Sciences]: Health

For reasons of space and focus, this paper is mainly concerned with eHealth as an example of Sensitive HCI, but the issue of emotional labour is relevant in the wider HCI context beyond Sensitive HCI. Performing a role in a collaborative or work context always requires some extent of acting to evoke emotions in others or to suppress them in oneself. While Hochschild's classic study focuses on flight attendants, in HCI, emotional labour has been studied in contexts ranging from collaborative editing [16] to the sharing economy [21]. In apps such as Lyft, drivers are often rated based both on the quality of the driving and their skill in evoking a welcoming atmosphere.

Motivation: Zawadhafsa's Story

For the dissertation component of her Master of Science (MSc) in Cognition, Science, and Society, Zawadhafsa wanted to explore to what extent the psychological notion of sense of agency affected whether Tanzanian women subscribed to a health insurance product that was provided by the mobile payment provider that these women used [17].

Zawadhafsa and her supervisor, Maria, settled on a design that consisted of a telephone survey, which included standardised questionnaires, and follow-on interviews of subscribers and non-subscribers. Project managing the administration of the survey was very stressful. As this was the capstone project of her MSc, Zawadhafsa was worried about recruiting a sufficient number of participants, and some people failed to attend scheduled interviews or were not interested in the telephone survey. To make matters worse, an intermittent internet connection made it difficult to enter the telephone survey data into a secure online form, which had been implemented using Qualtrics, for further analysis.

When Zawadhafsa returned from her fieldwork in Tanzania, she was visibly shaken by the personal stories that some of the non-subscribers had shared with her. Since Zawadhafsa (correctly) framed her work as a psychology study, some of her participants had assumed that she was a psychologist who could help them, and poured out a lifetime of abuse—even though the interview guide had not been designed to elicit such information. She also found that participants kept contacting her, as she had given out her own phone number, even though she had made it clear to participants that she couldn't help women escape from their domestic misery.

Surfacing the Emotional Labour of eHealth Work

What was required of Zawadhafsa has been described in the feminist literature using the concept of "emotional labour" [22, 23]. She had to enact the role of a research psychologist conducting a quasi experimental study, even when the women who confided in her saw her as a psychologist-healer. She had to maintain professional boundaries both to protect herself and to be able to fulfill her role as researcher in the face of abject misery.

Zawadhafsa and Maria discussed several ways to cope with this experience while preserving the emotional strength to write up her dissertation under time pressure. Key decisions were to deprioritise interview transcription, especially of those that were traumatising, even though this meant a greater focus on the survey results themselves, and to report the emotional labour of the interview process when discussing preliminary findings from the qualitative work. Maria also suggested counselling.

One might argue that this sort of experience was to be expected, since Zawadhafsa was working with potentially vulnerable participants in a developing country. This is one of the key sensitive contexts that have been identified by researchers such as Waycott and colleagues [25, 7]. But participants are often vulnerable and sensitive in unexpected ways, which may not be clear to researchers until they are in the field [4]. Participants may also use research as a resource for help, especially if they regard researchers as trustworthy, and if they feel they cannot access any support in their own communities. This is what happened in Zawadhafsa's case.

In this paper, we argue that emotional labour is pervasive in eHealth work. In designs where researchers' emotional reactions are an acknowledged part of the process, it can be hard for researchers to maintain safe boundaries [4]

while trying to fulfill the role of supportive facilitator. Conversely, in designs using a more objectivist framework, researchers may struggle with their role as recruiters, data collectors, and data processors in the face of uncooperative, distraught, or forgetful participants and/or intensely upsetting data.

There are no easy solutions for supporting this kind of emotional labour. Based on a review of the literature, and relying in particular on Petra's previous work [4] and Moncur [18], we outline a process for identifying and supporting emotional labour in eHealth research that can be extended to other areas of HCI as well.

The issues we discuss here for eHealth apply to all researchers in Sensitive HCI [25]. When looking for examples in a different application domain, we recommend the relevant ethnographic and anthropological literature, where researchers are more likely to discuss their emotional labour openly.

What is Emotional Labour?

> Emotional labour is the silent work of evoking and suppressing feeling—in ourselves and others. [22, p. 333]

I often felt ashamed of my emotions and I pretended to always be strong when I was with the [palliative care] team, because they were so confident and stable in the worst situations, like super heroes. Then, I discovered I was not alone in being ashamed of vulnerability.

[8, p. 5]

In eHealth research, we create safe spaces for people to express their attitudes and emotions towards the technology and their health. At the same time, we are moved by other people's health problems and the effect on their lives, we are forcefully exposed to the socioeconomic inequalities that reinforce ill health, and we witness suffering and are unable to relieve it.

Yet, we need to suppress feeling in order to function as researchers. Professional boundaries may preclude individual

participants [4], despite their evident need. Those of us who have the condition they are studying also need to suppress feeling when engaging with the scientific literature, where they may learn about aspects of their condition which they might have preferred to ignore. For example, Maria both lives with and studies chronic depression. Since she works as a researcher at a university, she needs to perform emotional labour when processing her reaction to any evidence that depression negatively affects cognition.

One way of coping with these demands is to create professional distance between oneself and the subject under study. However, dealing with sensitive topics and vulnerable participants requires openness, empathy, and reflexivity [29, 1, 2]—and reflexive, emphatic research comes at (sometimes great) cost to the researcher [24]. Many researchers have reflected on their vulnerability to emotions that need to be managed, and how this affects the entire research process [10]. Yet, researchers repeatedly report feeling ashamed of their humanity, their emotions.

In traditional quantitative study designs, researchers collect, analyse, and publish data from participants using strict protocols. However, this does not prevent researchers from having to perform emotional labour. Wilkins [26] describes the issues that arose in her work on maternal health in great detail, touching on the intricacies of navigating informed consent, and negotiating participation in the study.

Randomised controlled trials (RCTs) in medicine are set up to eliminate subjectivity and mitigate the influence of emotions as much as possible. Yet, we are starting to see evidence that this requires substantial emotional labour from the people who are working on the trial [9, 13]. This evidence is emerging as part of the drive to supplement RCTs with qualitative work that captures staff experience and seeks to understand how interventions to be studied

are implemented in practice. The extent of emotional labour involved can come as a surprise to research teams:

> [The] exploitation of emotional labour [is] the managing of hearts for the company good. [22, p. 329]

In addition to the intrinsic pressure of wanting to do their job well, there is substantial extrinsic pressure in today's high-stakes academic environment, with pressure to generate grants, impact, and publications in illustrious venues [4]. Recruiters in RCTs have to market their study convincingly to prospective participants. If recruitment goals are not met, the whole expensive study risks being underpowered, and consequently of low quality. Qualitative researchers are under pressure to conduct as many interviews as possible in a short amount of time, and take advantage of co-located interviewees to minimise travel costs, even though they may well need a day or two between interviews to ensure they are fit for the emotional labour of interviewing again [10]. The female Wikipedia editors studied by Manking and Erickson [16] sometimes dealt with untenable emotional labour by removing themselves from the stressful context. Researchers cannot do this.

Emotional Labour Throughout the Research Process

We have seen that while emotional labour is more obvious and prominent in more reflexive approaches to eHealth research, it is almost always present, even in designs that are intended to be as objective as possible. We now turn to discussing how it affects the research process, using the example of the final pilot trial of Help4Mood [5]. Help4Mood was designed to support the care of people with mild to moderate depression in the c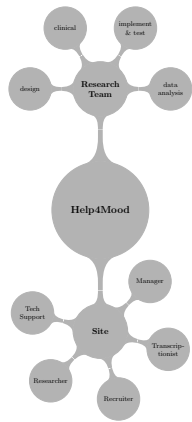ommunity, and it was tested in a pilot trial where 27 people from three countries were randomised to two conditions, intervention plus usual care, where they used the system for four weeks, and usual care, where they did not receive the system at all. Figure 1 shows the steps of the research we will be considering, and the teams at each site that performed emotional labour.

First of all, it is important to consider how the research topic might affect you before committing to it. Researchers are often passionate about issues that they have experienced first or second hand, but this also makes them vulnerable. Although, as several reviewers mentioned, Ethics applications require ticking boxes that say researcher wellbeing has been considered, these boxes focus on physical and cognitive labour (general health and safety, lone working), not on emotional labour [4].

While feminist, participatory, and activist research designs leave researchers more open and vulnerable, fields that espouse those methods also tend to value reflexivity, and have a history of talking about emotions in research. In research designs and contexts that emphasise researcher objectivity, it is much easier to be blindsided by emotions and feel the need to work hard to suppress them, because they are regarded as unprofessional.

Perhaps more important than the choice of research process is the choice of research team. If the researchers, investigators, technicians, and administrators can mutually support each other, emotional labour is much easier than where this is not the case [11].

For the Help4Mood trial, for example (see Fig. 1), each of the three site had an overall principal investigator and/or manager who was responsible for meeting targets and timelines. They worked with colleagues who recruited people with depression onto the trial and distributed materials

[. . .] The team I was part of always includes staff interviews in their projects to get a different view of how things went [. . .], so we were just really doing that. But after the first few interviews it was clear that recruitment and randomisation had been a really stressful experience for staff, and so we started looking at the interviews to see if there was anything significant emerging, [. . .] In hindsight it's kind of obvious, but not at the time.

Jackie Kirkham, comment in The Research Companion Facebook group, November 30, 2016, on the genesis of [13]

Figure 1: Parts of the Randomised Controlled Trial Process that require emotional labour and the people who perform it - the example of Help4Mood

(recruiters). Researchers visited people who volunteered for the trial, determined whether they met inclusion criteria, handed out the Help4Mood system and took it back at the end of the trial. Team members also transcribed interviews, and provided technical support. Fortunately, within Help4Mood, most of the field researchers were experienced, but often, it is junior researchers who are sent to do the time consuming labour of data collection, or students like Zawadhafsa undertake data collection for their thesis.

Implementing Technology
Planning Research
The technical team who create and code eHealth technology are often overlooked, because they are not in direct contact with participants. However, if members of the technical team have the condition to be addressed themselves, or know people with the condition, they are likely to experience strong emotions which they may have to suppress in order to be reliable professional coders. We are not aware of any qualitative studies, but would like to illustrate the complexity with one example.

Even though Maria has depression, she is highly functioning and has worked throughout her illness. One day, she was cross checking the design of one of the clinical components of Help4Mood when she was unexpectedly badly triggered by design elements that had been taken from standard clinical practice. She had to calm her emotions in order to be able to continue her work. Her colleagues supported her in this task, and this in turn enabled the team to use Maria's strong reaction as data, discussing what might similarly affect users of Help4Mood, and implementing appropriate modifications.

Data Collection
When in the field, it is key to be clear about boundaries. This can be a particular problem for junior researchers, who

are under pressure from the investigator team and from participants who ask them for favours [4]. To some extent, this can be mitigated by identifying difficult situations and rehearsing them. Such situations include taking away the eHealth solution, if it was only intended to be deployed and supported for a limited time, telling people that they do not qualify for a study because they are too ill or not ill enough (which often happens when there are clear inclusion criteria), or telling people that they have been randomised to the control condition, and will not receive the eHealth solution at all (or only much later). All of these situations may leave participants angry, upset, downcast, hopeless, or recall previous bad experiences with the health and social care system. The emotional labour here typically consists in giving participants space to express these emotions and support them in coping with them, while suppressing one's own rage at the inflexible study design.

Instances of harassment, stalking, and trolling on social media are even more problematic [4]. This occurs more often than one might think. Researchers are particularly vulnerable when working on or through social media. It is very easy for people to find researchers' email addresses and social media handles. Like the female Wikipedia editors in [16], researchers may feel that their behaviour has to be beyond reproach.

Data Analysis
Data analysis is another source of emotional labour. Whenever analysts and transcribers work with potentially distressing data, they need to ensure that their own emotions are either sufficiently calmed, or that they are able to maintain a reflective position which allows them to work through and with their emotions in their analysis.

Speech samples from people with depression need to be transcribed and analysed phonetically by humans, as fully

automatic analysis is often insufficient for the kinds of precise data speech scientists need. Depending on the data set, this means that analysts need to listen to stories of despair, or listen to numb or distraught voices, which can be very difficult for transcribers [6]. Not even relatively impersonal tasks are exempt. One of the recordings Maria analysed for [27] consisted of a person sobbing while they named different types of animals for sixty seconds. As a consequence, speech scientist Julian Epps has put together a package of counselling and supervision for researchers in his team who work on mental health data (Epps, personal communication).

Similar issues affect those who transcribe interviews and focus groups, who may be exposed to potentially distressing tales without warning [12]. If transcription is contracted out of the research team for cost and efficiency purposes, there is often no way to reach out to transcribers to provide additional support. If the researchers who collected the data transcribe it, they may be forced to relive profoundly distressing stories and difficult incidents. The risk of retraumatisation was one of the main reasons why Maria and Zawadhafsa decided to deprioritise interview transcription, so that Zawadhafsa could focus her emotional resources on completing her thesis.

Last, but not least, qualitative analysts who immerse themselves in a data set with upsetting incidents and stories will be exposed to these potential triggers repeatedly, and this will be even more intense if the analyst also collected and/or transcribed these data [15, 28]. Compared to the difficulties facing those who "only" collect or transcribe data, analysts' emotional labour is more intensive and spread over a longer period of time.

Designing a Support Process

Perhaps the most common reviewer feedback on this paper was "And where is the solution?". The overwhelming consensus of the research on the topic of emotional labour in research that we consulted for this paper was that there is no such thing as a single solution. Rather, researchers need to put into place a process for themselves that is tailored to the specific context in which they work.

This process is typically very specific to the piece of work and the researchers involved, and needs to be flexible enough for adjustments throughout the research journey. Much of the emotional labour comes unexpectedly. Zawadhafsa's interview schedule was not designed to probe deeply why her participants showed a sense of agency, because this was not her main aim. Yet, because she correctly described her work as a psychology study, some of her participants took this as a cue to unburden themselves in the interview, describing cycles of oppression, violence, and abuse.

In order to create such a process, researchers need three ingredients: an attitude of **kindness and acceptance** that allows researchers to identify where they have fallen short; a supportive **team** that makes it acceptable to show weakness, that allows for appropriate debriefing and support, and that can ideally also push back against potentially damaging institutional requirements; and a **reflective practice** that allows researchers to identify sources of emotional labour and methods for performing that labour while protecting themselves.

Component 1: Kindness

The first step is to accept that eHealth work stirs emotions. It is normal to be human [8]. The reflexivity that we demand from ourselves needs to come from a place of kindness, and mindful acceptance. It is possible to prepare for some

of the emotional labour that will be required during the process. In particular with highly formalised processes like RCTs, there is a lot of tacit knowledge about stages of the data collection process that could stir strong negative emotions in both participants and researchers, and this knowledge is being explicated in the trial literature [9, 13].

During and after the research process, emotional self-care is key [20, 18]. The most basic method is to establish regular self-care rituals, ranging from regular running to long baths [10].

Self-care also needs to be factored into the research process itself. For example, meetings with participants for data collection should be spaced so that the researcher can recover emotionally. In the context of emotional labour in the work place Russell Hochschild also suggests acting out a pre-defined role as a strategy. While the suggestion to act or role play runs counter to the requirement that researchers be as sincere as possible, sometimes, role playing can form a useful protective barrier around a person performing emotional labour.

Component 2: The Team
Without a supportive team, a reflective practice and an attitude of kindness to oneself can be extremely difficult to implement. Identifying potential team members can be a tightrope act, especially when it comes to involving people who have power over the research, such as Principal Investigators or supervisors. For every story where a senior team member would have been incredibly supportive, had they only known [20], there is a story where junior members' concerns were disregarded [4].

One of the main functions of the support team is debriefing. This can happen within the research team, through long chats with colleagues from the same field, and through more formal processes of supervision and regular counselling. Often, researchers arrange these debriefing opportunities themselves informally. Rager [20] notes that she would have been able to ask her PhD committee chair for support when she struggled with the emotional labour of talking to women undergoing cancer treatment, but only realised this when it was too late. Instead, Rager arranged her own counselling, and discussed her strong emotional reactions to women's stories with a peer in whom she felt she could confide. The procedures suggested by Epps, on the contrary, explicitly include regular supervision and debriefing as well as access to counselling as part of the standard research process.

Component 3: The Reflective Practice
Reflection has long been a part of qualitative research. Reflective techniques ranging from journalling (e.g. [14]) to letter writing [19] are possible ways of acknowledging the emotions that surface during research and exploring them safely. These techniques can also allow the research team to share coping strategies and observations. Most importantly, researchers can use reflection to find out what support mechanisms are working for them, why, and how lack of self-care might affect the research process. A detailed case study of this can be found in the autoethnography shared in [10].

However, reflective practice can also be an invitation to ruminate and focus on one's shortcomings, if done without (self-) acceptance and kindness (Component 1). Therefore, it is important to use reflection carefully, in a way that suits the researcher's individual coping stype. Some people do need to debrief and offload. Some find it helpful to do this within a group setting, others on a one-to-one basis. The team (Component 2) can ensure peer and professional support is available as and when needed.

> *[. . .] it is important that researchers feel that they do not have to manage the emotional impact of their work on their own but can rely on the support and advice of colleagues in the wider work environment.*
> [11, p. 134]

Why Are We Doing This To Ourselves?

So why should researchers do this emotionally demanding, labourious work? The oft-cited answer of the anthropologist Ruth Behar is that work that breaks your heart is the only work worth doing [3]—if work arouses strong emotions in the research team, this is an indication that the work is important.

Behar's point touches on another important aspect that has surfaced repeatedly as we have discussed emotional labour in practice: The researchers' emotions are an invaluable layer of data that can inform and guide the process of design and analysis [11]. Maria's strong reaction catalysed a discussion of potentially upsetting design decisions, and Zawadhafsa gained an in-depth understanding of the brutal realities that some Tanzanian women face. This understanding informs both her ongoing analysis of the data, and the direction of her subsequent work.

In order to provide space for this emotional labour to bear fruit, we need to challenge a culture of research where empathy is treated like a commodity, and research as something to be produced in ever more impactful and easily measurable units. Grant awarding bodies and governments push researchers to work on issues that are relevant to society, and to focus on chronic illnesses such as depression, dementia and cancer that can be great personal tragedies for those affected. And, because these conditions are so prevalent, it is highly likely that researchers may either have the condition themselves, or have a close family member or friend who is affected. All of this greatly add to the emotional labour necessary to perform the researcher role.

We also need to sensitise our students, the next generation, to the demands that eHealth work in HCI (and indeed, any work with vulnerable participants in Sensitive HCI) will make on them, so that those already under massive stress due to coursework deadlines won't do unneccessary emotional labour in order to maintain the fiction of the calm, competent researcher.

The team which provides a safe space for emotional labour needs to be wider than the immediate research project group, it needs to extend to the whole community. Qualitative health researchers, ethnographers, and anthropologists have already initated a lively discourse, and the HCI community needs to integrate the emotional labour of researchers into its vigorous discussion of ethical and sensitive research, and into paradigms such as Feminist HCI.

Supportive dialogue between researchers is key. While the temptation may be great to just add an additional box to Ethics applications, or lines to risk management plans, without a culture that takes emotional labour seriously, the additional paperwork is meaningless. We hope that this paper can fuel such dialogue in all areas of HCI, not just eHealth and Sensitive HCI.

Acknowledgements

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