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# Ethnography in Healthcare: Ethical Responses when the Unexpected Happens

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**Abstract**

HCI researchers often conduct an ethnographic study of healthcare interventions in real clinical settings as a prelude to developing computing systems to support those clinicians in their work. Standard ethics committee oversight and approval provides an ethically appropriate environment that protects the patients and the researchers. This position paper goes further to look at the ethical responsibilities of the researchers when unexpected events happen during those studies. We focus on taking an ethical approach to reporting on unexpected events. We use four examples to illustrate a range of possible reporting options and to highlight the need for the HCI researcher to properly consider the wider context of the unexpected event, its relevance to the research aims that the ethnography is supporting and the possibilities of an audience misinterpreting that reporting.

**Author Keywords**

Ethnography in HCI; Healthcare; Ethics

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H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous

## Introduction

Ethnographic methods can provide powerful tools for communication between HCI researchers and healthcare professionals as they work together to develop new interactive systems for the health sector. The clinical work that healthcare professionals do depends on extensive training, prior experience and the immediate situation and context of each patient. Allowing the HCI researchers to observe clinical interactions with patients in the actual clinical settings, to gather data from those observations and to reflect on and iterate over that data can provide the HCI researchers with important levels of understanding of the clinical tasks, contexts and constraints.

As discussed in a paper at an earlier version of this workshop [2] HCI research with actual participants requires active management by the researchers of the risks involved. In terms of the spectrum of risks over the range of HCI research activities, working with clinicians and patients in an actual clinical setting has the potential for high levels of risk. Planning for these risks in HCI research is a central concern of the relevant Human Ethics Research Committee (HREC). Where the research involves clinical intervention, even in a detached ethnographic sense, the HREC will typically require extensive thought and planning before it gives its approval.

The resulting ethics approval is, however, a static document. It addresses the foreseeable. Clinical interactions with patients are not necessarily entirely predictable and the focus of this workshop paper, in the context of ethnographical studies of clinical practice, is on the ethical responsibilities of the HCI researchers when the unexpected happens.

Specifically, this workshop paper focuses on how HCI workers in healthcare projects represent unexpected events from their ethnography in their field notes, discussions, presentations and publications. We will look at three aspects of such unexpected events:

- The particular clinical situation in which the event occurred
- The relevance of the event to the purpose of the ethnographic study
- The scope for an audience to mis-interpret the observations relating to the event

The position of this paper is that, particularly in a healthcare setting, HCI researchers have an ethical responsibility to properly consider these aspects when they publish results from ethnographic studies in healthcare settings.

In the following sections we will:

- Use a Participatory Design perspective to illustrate the trust relationships that might form when HCI researchers and healthcare professionals work together
- Illustrate the three points that are listed above using examples of observations from our work with surgeons
- Discuss the overall issues that emerge from these illustrations

## Participatory Design as an ethical framework for HCI Research in Healthcare

When HCI researchers and healthcare professionals work together to explore the possibilities of developing interactive computer systems for healthcare they

typically bring high levels of complementary skills to the project. This suggests that a Participatory Design approach is the appropriate way for them to work together. In particular, it is important for the HCI practitioners to demonstrate a high level of respect for the clinical skills and knowledge of their project partners and to take steps to understand their work practices.

The chapter by Robertson and Wagner in the Routledge International Handbook of Participatory Design [1] discusses the participatory design process in terms of ethics. The authors list three principles that underlie Participatory Design. First, “the people who do a particular activity ... know most about how it gets done”. Secondly, that the stakeholders should “learn from each other through understanding each other’s perspectives and priorities”, and thirdly, “people have a basic right to make decisions about how they do their work”. In applying these principles to the engagement between participants the authors raise the importance of “mutual trust” [ibid, p72].

This issue of trust gives the HCI researchers a way to guide their reporting of what they see and how to interpret what they see when they conduct ethnographies of healthcare delivery. The clinicians need to know that they can trust their HCI collaborators to represent the events that occur in an ethical manner.

### **Example Observations in a Healthcare Setting**

#### *Complex surgery to remove an abdominal cancer*

This case involved removing a cancer that had distorted the patient’s internal anatomy and had attached itself to a major blood vessel. During the three hours of

preliminary surgery there was an “Oops” moment when a blood vessel was damaged and the operation was diverted for a few minutes to repair it.

In this particular case there was a known set of problems with the patient’s blood vessels around the cancer, which was why the lead surgeon had an experienced vascular surgeon to accompany him during the surgery. The timing of the “Oops” moment may have been unexpected but the event itself had been properly prepared for and was handled without fuss in a standard manner.

The purpose of this set of observations was to gather background on the way that the particular surgical specialty worked in the operating theatre, with a view to understanding the scope for deploying additional information technology in the operating theatre to give those surgeons better access to the patient’s data.

The relevance of this event was that it highlighted how surgeons from different specialties might work together and it raised an open question about the need to support collaborative discussion about the display of the patient’s image data in theatre. It was important, however, to understand this “Oops” moment in its proper context. A simplistic representation of the event could easily be seen as casting doubt on the skills of the surgeon or the quality of the particular hospital. The “Oops” moment remained as a private item in the researcher’s field notes but it was a valuable observation that prompted further discussion for the ongoing project.

### *Visualisation tools to support minimally invasive surgery*

Following an international demonstration of the use of a 3D virtual reality headset and stereo laparoscopic camera for minimally invasive surgery we interviewed surgeons in the audience about the comparison between this 3D viewing method and the traditional 2D screen display that supported mainstream minimally invasive surgery. One senior surgeon commented that he, in fact, did not have stereoscopic vision and he used the rich range of other depth cues for his view of the 3D world.

This comment was relevant in that it raised an issue that we had not considered – that some surgeons might be better suited to the mainstream 2D displays over the novel 3D camera and display systems. We discussed this issue at an internal seminar on our work soon afterwards and we found that the audience was not prepared to accept that someone with a “deficiency” in their visual system might actually be a highly skilled surgeon in a context where that “deficiency” did not come to play.

That same surgeon had also made strongly positive comments about the possibilities of a mature 3D display system, such as might be developed out of the research system being demonstrated, and we focused on these in our publication [3].

### *A problem arising during surgery*

We had been exploring the concept of using gesture-based display technology to let the surgeon study the patient’s scan data (CT, MRI, etc) during surgery to deal with *ad hoc* problems should they arise. In the types of surgery that we were studying, problems that

required the surgeon to refer to the patient’s scans during surgery were rare. The premise of our investigation was that in such events the surgeon himself or herself might want to take immediate control of the display of scan data rather than relying on assistance from others in the operating theatre.

Such an instance actually occurred during one of our observations. The surgeon was inserting internal grafts into the patient’s arteries using catheter-based procedures and, at one point, he had trouble passing the guide wire into a branch artery. After several attempts the surgeon decided to consult the patient’s 3D scan data on a computer in the annex to the operating theatre.

The surgeon asked the representative of the company that had supplied the grafts to operate the computer. It was clear that this person was under a lot of stress (his company’s product might be causing the problem) to the point where he was unable to follow the surgeon’s instructions. The surgeon finally resorted to simple “up arrow” and “down arrow” instructions and the problem was resolved.

From the point of view of our research this was an extraordinarily valuable observation. It highlighted the need for the surgeon to have direct control over the scans’ display and it clearly showed the impact of stress within the operating theatre upon such an event, something that had not previously been reported. Our challenge was to report the event in a way that showed the value of our observations but that correctly presented the nature of the situation and the behavior of the participants.

Specifically, it was important to make it clear that this was an unusual type of operation, that the surgeon was in control of the situation the whole time and that he had a process and the skills to deal with it. It was also important to avoid any implication that the company or its representative might in any way be at fault. We note here that the surgeon involved reviewed the draft document that covered this event and approved its publication [4].

#### *Observing a post-operative outpatient clinic*

This example occurred during a pilot study of telehealth support for outpatient clinics at a tertiary-level children's hospital. The study was conducted within the hospital, using two meeting rooms to represent the telehealth situation, and with a follow-up face-to-face meeting between surgeon and patient/family to ensure that nothing was missed during the telehealth phase of the consultation. The selection criteria for inviting patients to take part were that the consultation would be a review of progress after surgery and with no major decisions expected. This very conservative approach satisfied the hospital's ethics committee because it minimized the risk of difficulties arising during the telehealth phase of the consultation, even though there was a follow-up face-to-face phase in the protocol.

The unexpected event was that the invitation to take part in the study had been sent to a new patient, and the new patient/parents had accepted it. This only became apparent when the patient arrived for the consultation. The surgeons (there were two surgeons working together that day) decided to proceed with the telehealth consultation knowing that they would have the opportunity for a regular face-to-face meeting with the patient to deal with any outstanding issues.

The telehealth phase of the consultation was very successful. The patient had multiple conditions and the surgeons were able to assess the situation and plan for specific diagnostic follow-up for each condition, exactly as they would have if the patient had first presented over a telehealth link from a remote location, and with the same outcomes as would have arisen if the consultation had been in a normal setting.

What this event illustrated was that the surgeons were not bound by a fixed protocol in this exploratory ethnographic setting. Even though the patient was not in the target category for this study they made a decision that it was in the best interest of the patient and family to proceed with the telehealth consultation and face-to-face follow-up, rather than send the patient home and reschedule for a normal consultation.

In terms of research outcomes, this event broadened our understanding of how these highly specialized outpatient consultations might map into a telehealth mode of delivery. We reported this event in terms of broadening the surgeons' understanding of the possibilities of using telehealth in their practice [5]. Our phrasing was carefully chosen so as to not imply criticism of the hospital's administration "We saw the surgeons initially identifying barriers to being able to conduct their clinics (requesting changes be made to the telehealth system, ruling out certain classes of patient), and we later saw them relax these barriers as they gained experience in using the system [ibid]."

#### **Discussion**

These examples show that there is a range of possible reporting of these unexpected events, from keeping them private to the researcher's field notes (the "Oops"

moment), discussing them only within the immediate team of researchers (3D depth perception), presenting the learning outcomes in publications (the patient who did not fit the exact selection criteria) and publishing the full details and context (consulting the patient's scans during surgery). The HCI researchers will be aware that an unexpected event has occurred and their ethical responses should be to carefully consider an appropriate level of reporting.

These examples also show a range of possible causes of these unexpected events during clinical healthcare. Some clinical procedures are complex and inherently uncertain, and there will be procedures to handle unexpected events. Some may only be a surprise to the HCI researchers, such as the comment from the surgeon about using different visual 3D depth cues. Others may arise from simple clerical errors, such as having two patients with the same name. It is important for the researcher to look at the underlying situation before making decisions on how to present the observations, even discussing it with the clinician involved.

In each case of an unexpected event during observations of healthcare interventions the ethical approach for the HCI researcher is to consider the broader context and causes of the event, the knowledge to be gained by reporting the event and the risk of mis-interpretation of such reporting by a wider audience. A specific ethical approach that is worth considering is to actively record the wide range of observations that an ethnographer would expect in these complex healthcare settings, to keep the raw observation data private to the researcher and to focus on reporting the "gained insights" from that data (the

author acknowledges one of the anonymous reviewers for this phrase). These gained insights should then embody the primary purpose of the observational study, the context in which the events occurred and the ability of the target audience to understand and interpret those insights.

A second aspect is for the ethnographer to arrange for confidential reviews of his or her work, with an explicit focus on the ethics of the work, prior to submission for publication. The author has often taken this approach, ranging from reviewing field notes for accuracy and completeness with the clinician through to giving the clinicians full drafts of the papers to be submitted.

Both of these aspects require the authors to make deliberate and mindful choices about what they write and these choices need to address the purpose, the context, the insights and the audience.

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