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The Everyday Ethics of Field Work Research with Vulnerable Patients

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Abstract. Patients are increasingly involved in health informatics research. Researchers are always aware of the ethical dimensions of their research, but studies in the field with patients – especially among the frail, elderly, cognitively impaired - present specific additional 'everyday moral dilemmas'. Reflecting on experiences of a hospital study of patients with dementia, this paper draws attention on the type and constant presence of this situated ethics, the immediacy of decision-making, and the importance of everyday ethics for health informatics.

Keywords. Health informatics, research methods, ethics, patients

Introduction

There is an increasing interest in health informatics research involving patients. For example, health IT implementations are evaluated in terms of patient outcomes, or research is carried out to design or evaluate patient-facing technology intended to assist patient decision-making, or for self-management, self-care, or assistive purposes (e.g. [1, 2]). Health informatics research thus calls for an increased "focus on patients' perspectives" [3] and direct involvement of patients as end-users [4].

Ethical issues[1] permeate research with patients, especially among the frail and elderly, or cognitively impaired population. Yet it could be argued that these vulnerable people[2] would gain the most from technological innovation, for example to help them maintain a degree of independence and autonomy. Furthermore, being involved in research would give them a voice often otherwise silenced [7].

"Ethics is an ever present concern for all researchers" [8:567]. The health informatics literature has explored issues of ethics pertaining to research on patient data (e.g. [9, 10]), but few are the studies exploring the ethical issues related to directly involving patients (e.g. [2, 11]). In this paper, I draw attention to some of the everyday ethics dilemmas faced by a researcher in this field, using examples from an on-going study in hospital wards in England (UK). While this study is not specifically aimed at implementing patient-facing technology, the research experience resonates with, and is relevant to, studies in this area.

[1] In this paper I am interested in ethics with a small e, "the moral what-to-do questions […] that require […] to evaluate and choose between alternatives" [5:48] on an everyday basis, while in the field. This is also known as 'everyday ethics', 'ethics in practice' or 'microethics' [6]. It is not the Ethics with a capital E of Ethics Committees or Ethics Councils.

[2] Some of the situations discussed in this paper are specific to research with vulnerable people. But it could be argued, all patients are vulnerable.

1. Methods

This paper is based on research in the field I am currently conducting for a study aimed at the design and implementation of a decision support tool for the assessment and management of pain in patients with dementia[3]. At the time of writing, the study is taking place in 4 NHS hospital organisations in England and Scotland. Inpatients of 2 hospital wards per site – and the care they receive - are our unit of analysis. Qualitative data are being collected with a mix of methods including observations, documentary analysis of patient hospital records, and interviews with clinical staff, managers and carers. This paper is based on personal experiences of collecting data in one of the 4 hospitals – in an elderly medicine ward and a vascular ward. This included the recruitment and observation of 8 patients and audit of their hospital records, 71 hours of observations at the patient's bedside (over 22 days, in the period from May to November 2013), and about 124 hours of observation of the ward context. Observations of patients and any interactions they may have had, were carried out at the bedside for up to 3 days. Thus, relations with the patients in this study did not benefit from familiarity built over long periods of time [12], but over relatively brief research encounters.

The patients included in the study were elderly and had a diagnosis of dementia. Their consent to participate was subject to capacity assessment to consent, consultation with staff and assent of carers [13]. The process was agreed with NHS Ethics Committees in England and Scotland and informed by the Mental Capacity Act 2005 and the Mental Health (Care and Treatment) (Scotland) Act 2003 [4]. Ethics Committees approval and oversight provide some assurance about the ethics of these research activities, but they do not free the researcher from judgments and decisions of ethical nature while in the field. As it has been said, "It is at the level of 'ethics in practice' that researchers must do the real ethical work" [6:273].

2. Results

2.1. Consenting, then leaving them

The first encounter with the patient was fraught with moral dilemmas. Both the situation of being hospitalised, and their cognitive impairment, influenced their ability to consent freely. The same conditions also influenced relatives or carers' assent. More than once, relatives/carers expressed hopes or wishes for the researcher to provide their elderly relative with some company and opportunities for interaction while in the hospital. Thus they qualified their assent for study participation and by doing so created expectations that were outside of the remit and role of being a researcher.

Observations at the bedside were limited to three days for each patient. I was 'company' for three days, and then I left; and I may have left them to boredom or distress, posing a further dilemma. And so, on occasions, I stayed, for a few more hours.

[3] "The detection and management of pain in patients with dementia in acute care settings: development of a decision tool" (HS&DR - 11/2000/05) http://www.nets.nihr.ac.uk/projects/hsdr/11200005

[4] http://www.legislation.gov.uk/ukpga/2005/9/contents, http://www.legislation.gov.uk/asp/2003/13/contents

I find the nurse with [the patient], she is putting his boots on and he seems angry and in distress. He wants to go home. As the nurse leaves I talk with him, as I realise he has seen me. He wants to leave the hospital …. We end up chatting until 4pm.

These points of initial contact (informed consent) and points of departure (leaving the participant) highlight some of the ethical challenges of doing research with patients. Patients and relatives had different and varied reasons for accepting to participate in the study [14] and through their reasons they gave my work a different dimension. While I was conducting research, I was also fulfilling other functions, such as providing company and interaction; this potentially created situations of 'dual agency' – potentially "conflicting duties or loyalties" [15].

2.2. Observations and Interventions

On repeated occasions during observation sessions patients or staff asked me to intervene. This raised another dilemma; *Was it right to say yes? Was it right to say no?* Small acts of 'participation' (intervention) could be associated with harm. But the opposite was also true, and harm could have been associated with non-intervention.

He kept falling asleep on the chair. And when awake, tried to get out of the chair. I told him to wait and went looking for somebody to help him. At the nurses' station the clerk said there is a risk of falling, not to let him get out of the chair. When I explained that I was not authorised to intervene she said she isn't either but that better to intervene than to have a fall. So I went back to the patient and thought that if I engaged him in conversation he would stop trying to get up …

Another patient […] returning to the chair from a visit to the toilet, asked me if I could help her. I offered her my arm. […] Though I did wonder what would be the consequences if she fell while I helped her.

On other occasions it was the situation that demanded action.

A patient all of a sudden starts breathing deeply and crying out – ah! Ah! Ah! and rocking on her chair. I and another patient ask if she is okay. She says "I got this sudden spasm. Very frightening." She is still breathing heavily. I call the healthcare assistant outside the room for help, she gives her an inhaler and calls a nurse…

The meal lady asks [the patient] for tea or coffee and cake. [The patient] answers coffee […] the cup seems too heavy for her. Is she going to spill hot coffee on herself? I intervene: I take the cup off her hands. But if not helped, she won't have it.

Acute and explicit health and safety situations such as the patient's sudden lack of breath, were rare. Instead small scale everyday 'calls for assistance' were frequent and were those that created greater ambiguity in terms of ethical response. Additionally, they posed a methodological dilemma: intervening meant changing patient experience or the dynamic of the patient interaction with healthcare staff subject of study.

3. Discussion

As technology is increasingly ubiquitous, health informatics systems are designed for a variety of contexts; research is expanding its boundaries to settings involving directly patients – from hospital rooms, to people's homes – with different patient populations. The experience of carrying out data collection with this frail, vulnerable group of elderly patients has highlighted the complexity and potential ethical dilemmas researchers may face in these contexts. In my role as a researcher I intended to minimize the impact of my presence on the ward, conducting the field study in line with a non-participant research design. However, I found that there is no such a thing as *non-participant observation* in this kind of research. Just by being at bedside, my presence affected the patients' experience of their hospital stay and illness, and their interaction with the environment. Furthermore, either I found myself needing to intervene, or I was explicitly asked to. Thus I 'helped out' much more than I had anticipated - I called for help on behalf of patients, opened a door for a claustrophobic one, passed a glass of water to a blind lady, adjusted settings of TV sets, even caught a bee that entered the room on a summer day. Because of the hospital context and the patients' frailty, many of these interventions bore an element of risk for the patient, and therefore implied an ethical choice. In terms of patient recruitment, the choice has a 'hard' character of either/or - the patient either participates or not (though being then sensitive to cues of the wish of participants to withdraw from the study [14]). A more nuanced 'soft' range of choices is possible for questions of intervention, as intervention can take many forms. Thus, for example, in the case of the patient at risk of falling from his chair, my intervention took the form of engaging in conversation instead of actively stopping him from standing up. Although the study can be considered low-risk, bearing minimal risk for the patient, I was still at risk of invading their privacy and personal space, or contributing to (while trying to prevent) physical harm (e.g. from a fall). Choices were made on the basis of ethical principles of 'doing no-harm', respect for the person's dignity and recognizing the person's "inherent rights to privacy, respect and self-determination" [16:796]. I was aware that "participants can be wronged even if they are not harmed" [16:796]. Decisions were also informed by my understanding of the situation, empathy with the participants, and the relationship established with the patient in the brief time of our encounter. In everyday ethics, choice and outcomes are situated and contingent; dilemmas are resolved "situationally" – i.e. "considering the individual circumstances each dilemma encompasses" [8:568]. Furthermore, these situations are "integral to the entire research process and not just frustrating asides" [8:575]. These decisions are taken in a very brief time frame; they are many a "snap decision" [8:572]. "I began hastily to calculate my position" writes Goodwin recounting an ethic dilemma in the field [8:572]. But often there is no time to contemplate or calculate alternatives. There is no time to think beforehand, engage in reflexivity about the specific situation [6], or being fully conscious of the rationales for different options or the choice being made. This is a reason why researchers need to develop "ethical competence" and skills [6:269] – i.e. develop means of addressing and responding to ethical concerns if and when they arise in research [6:276]. It may be inevitable that the right – or the best - decision cannot always be made 'on the spur of the moment'. If in the field there is no time to think, reflecting on events and thinking about ethics whilst outside of the field can better prepare the researcher for the next ethical 'snap decision' to be faced. It can help the researcher gain 'a way of thinking', an 'alertness' to situated moral dilemmas [6].

Health informatics aims to use technology 'to make a better world' [17] improving healthcare and people's well being; we need ethical means for ethical ends, starting perhaps from small scale everyday ethics and field research.

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References

[1] T. Greenhalgh, J. Wherton, P. Sugarhood, S. Hinder, R. Procter, R. Stones, What matters to older people with assisted living needs? A phenomenological analysis of the use and non-use of telehealth and telecare, *Social Science & Medicine* **93** (2013), 86-94.

[2] A. Das, D. Svanæs, Human-centred methods in the design of an e-health solution for patients undergoing weight loss treatment, *International Journal of Medical Informatics* **82** (2013), 1075-1091.

[3] A.G. Ekeland, A. Bowes, S. Flottorp, Effectiveness of telemedicine: A systematic review of reviews, *International Journal of Medical Informatics* **79** (2010), 736-771.

[4] E. Bélanger, G. Bartlett, M. Dawes, C. Rodríguez, I. Hasson-Gidoni, Examining the evidence of the impact of health information technology in primary care: An argument for participatory research with health professionals and patients, *International Journal of Medical Informatics* **81** (2012), 654-661.

[5] Nuffield Council on Bioethics, Medical profiling and online medicine: The ethics of 'personalised healthcare' in a consumer age, Nuffield Council on Bioethics, London, 2010.

[6] M. Guillemin, L. Gillam, Ethics, reflexivity, and "ethically important moments" in Research, *Qualitative Inquiry* **10** (2004), 261-280.

[7] P. Fisher, Ethics in qualitative research: 'vulnerability', citizenship and human rights, *Ethics and Social Welfar*e **6** (2011), 2-17.

[8] D. Goodwin, C. Pope, M. Mort, A. Smith, Ethics and ethnography: an experiential account, *Qualitative Health Research* **13** (2003), 567-577.

[9] S.T. Rosenbloom, J.L. Madison, K.B. Brothers, E.A. Bowton, E.W. Clayton, B.A. Malin, D.M. Roden, J. Pulley, Ethical and practical challenges to studying patients who opt out of large-scale biorepository research, *JAMIA - Journal of the American Medical Informatics Association* **20** (2013), e221-e225.

[10] H.W. Samuel, O.R. Zaïane, D. Sobsey, *Towards a definition of health informatics ethics,* Proceedings of the 1st ACM International Health Informatics Symposium, Arlington, Virginia, USA, 2010, pp. 257-264.

[11] J. Galliers, S. Wilson, A. Roper, N. Cocks, J. Marshall, S. Muscroft, T. Pring, *Words are not enough: empowering people with aphasia in the design process* Proceedings of the 12th Participatory Design Conference: Research Papers - Volume 1, ACM, Roskilde, Denmark, 2012, pp. 51-60.

[12] C. Ellis, Telling Secrets, Revealing lives: relational ethics in research with intimate others, *Qualitative Inquiry* **13** (2007), 3-29.

[13] T.B. Monroe, K.A. Herr, L.C. Mion, R.L. Cowan, Ethical and legal issues in pain research in cognitively impaired older adults, *International Journal of Nursing Studies* **50** (2013), 1283-1287.

[14] M. Gysels, C. Shipman, I.J. Higginson, "I will do it if it will help others:" Motivations among patients taking part in qualitative studies in palliative care, *Journal of Pain and Symptom Management* **35** (2008), 347-355.

[15] K.W. Goodman, S. Adams, E.S. Berner, P.J. Embi, R. Hsiung, J. Hurdle, D.A. Jones, C.U. Lehmann, S. Maulden, C. Petersen, E. Terrazas, P. Winkelstein, AMIA's Code of Professional and Ethical Conduct, *JAMIA - Journal of the American Medical Informatics Association* **20** (2013), 141-143.

[16] Z. Ludin, *On ethical problem solving in user-centered research: an analysis*, CHI '11 Extended Abstracts on Human Factors in Computing Systems, ACM, Vancouver, BC, Canada, 2011, pp. 791-798.

[17] G. Walsham, Are we making a better world with ICTs? Reflections on a future agenda for the IS field, *Journal of Information Technology* **27** (2012), 87-93.