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History is bunk†

Invited commentary on... Re-evaluating confidentiality

Gwen Adshead

Draper & Rogers (2005, this issue) discuss the publication of case studies in psychiatry. They raise an issue in relation to consent that I would like to pursue in more detail: namely, what is it that we are asking patients to consent to when we ask them to participate in research?

Draper & Rogers suggest that minors and incompetent psychiatric patients pose similar problems for consent, not least because the publication of their histories is not in their individual interest. Although there are similarities with legal minors, I think that psychiatric patients differ from children in significant respects. Eliding the two groups is not helpful, because adults with psychiatric problems are not children, and there is a real danger that patients will feel patronised and controlled in demeaning ways.

But a more crucial issue is actually whether it is true that psychiatric patients (and, indeed, children) are *not* competent to consent to publication of data about them. This depends on what it is that we are asking them to do. I suggest that we are asking them (a) to take a small risk that their privacy will be invaded and (b) to do this for an altruistic purpose for the benefit of others.

Both of these decisions are more complex than most ordinary treatment decisions. Do they need a higher demonstrated level of competence? It is possible to argue that taking a risk to benefit others, without any possible benefit to the self, is a more demanding choice to make, in terms of duties, consequences, virtues and so on. *Prima facie*, it might seem that psychiatric patients and minors will not be able to do this. But the research does not bear this out. Priscilla Alderson's research shows that children as young as 10 can make complex treatment decisions, involving life and death (Alderson, 1992). Appelbaum (2004) cites evidence that patients with serious mental illness are still able to consent to research participation. It is a mistake to assume that psychiatric patients and children lack competence to make complex decisions; each person's competence will need to be assessed.

†This is the second of two invited commentaries on this article. For the first see pp. 122–123, this issue.

Consent

I have argued elsewhere (Adshead, 1997, 2003) that the choice to participate in research is fundamentally different from making treatment decisions, because it involves the decision to be altruistic. I have also argued that because of this difference, it is crucial to retain the distinction between therapeutic and non-therapeutic research. Draper & Rogers hint at this in their article, and I emphasise it because it has been suggested by our own College that this distinction should be dropped (Royal College of Psychiatrists, 2000). Quite apart from the fact that it is not possible to abandon conceptual distinctions just like that, the key issue here is about what it is that research participants are being asked to do, whether it is in terms of consent to disclosure for research, or consent to participate in a trial. For therapeutic research, the participant is being asked to help others, while taking a chance that they might benefit. For non-therapeutic research, participants are asked to help others, and take a chance that they may be harmed.

Clearly, researchers (including those who seek to present case histories) are under a duty to protect research participants as much as possible, and not

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expose them to unnecessary risks. But research is risky because it involves the unknown, and we ask research participants to take on that risk for the rest of us. Such a level of altruism must involve a free choice; it cannot be forced or else it will not be altruism. This is the ethical basis of the Helsinki declaration requirement that research participation is voluntary and participants can withdraw at any time (World Medical Association, 1964).

Researchers therefore need guidelines for carrying out any non-therapeutic research with those patients who do lack competence to take non-therapeutic research decisions, because they are going to be requiring them to be altruistic in ways that we ourselves would probably not be happy to do. Most of us would like to choose whether we help others or not, because the choice is emotionally and psychologically meaningful to us in terms of our values. There are several sets of guidelines in existence and they all contain the same advice: that it is ethically justifiable to include incompetent patients in non-therapeutic research because of the possible benefits to other patients in similar situations. However, it is only possible if the risk of harm (including exploitation) is small; I prefer to think of this as the risk of insult and injury.

The question then for case histories must be whether publication will cause the patient insult or injury. Draper & Rogers discuss the possible insults to a patient described in a case history in terms of 'violation', which seems to me to be right.

True fiction?

I want to conclude with some thoughts about 'credible' and 'true' fictional accounts of patients' stories. In one sense, the 'facts' about a patient's life are rarely crucial to the clinical narrative, in the way that they may be for other medical case histories. This is because many, if not most of the case histories that we seek to present in psychiatry are actually ethical dilemmas; that is to say, they raise questions about what psychiatrists should do, not what they can do. If a patient makes a fantastic response to a new treatment approach, for example, there is always a question of how competent they were to consent to something new. If a patient presents with an odd set of symptoms, then the facts of their case are only relevant insofar as they may offer other explanations for the symptoms. Psychiatrists are in an odd position of being able to consider, interpret and evaluate all that is known about a patient in different ways. The decision about whether to call some aspect of a patient's case 'abnormal' (and thus of clinical interest) is complex. This is not the case for physicians or surgeons, where the range of interpretation of abnormality is much smaller.

I found myself wondering therefore what 'truly fictional' accounts of a patient (Draper & Rogers, 2005: p. 119) might constitute in practice. The concept of 'true fiction' is an interesting one, and I can see why the notion of 'credible fiction' makes more sense in terms of publication of case histories. But I suspect that these are not concepts used in general medicine and surgery when case histories are being presented. What these concepts suggest to me is that case histories in psychiatry say more about the researchers, and their view of psychiatric practice, than anything else. The selection of historical detail, and the way such details are presented, create a very particular kind of story about the patient; one with which the patient, and others, may not agree. I take the view that psychiatrists are constantly creating narratives about their patients; narratives that change over time. In this sense, the psychiatric process resembles the ordinary historical process, which argues whether 'history' is a recording of facts or personal interpretations (Evans, 1997). Perhaps case histories should always be accompanied by other accounts of the patient's story, from other perspectives. This might take up more journal pages, but might do justice to the complexity of clinical decision-making in psychiatry.

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