

Confidentiality, Choice, And The Question Of Autonomy

By James Giordano, PhD and Nisha Dogra, MD, PhD



Nisha Dogra, MD, PhD

(for healthcare products, services, etc.) where an obviously false name is used, a subtle—or overt—message may be conveyed to others reflecting potential benefit(s) of disclosing personal identity and information in the public sphere. In this essay, we focus upon this trend, pose questions of whether confidentiality is an absolute requirement of the clinical relationship, address potential effects and implications of patients' waiving and/or disowning their confidentiality, and frame these issues within an appreciation of the scope and limits of autonomy in medicine.

The Intent Of Confidentiality

One of the key issues in the ethical conduct of both research and medical practice is the confidentiality of subjects' and patients' identity, and of the findings relevant to their case. In general, researchers and clinicians are obligated to protect the identity of their subjects and ensure that the parameters of such protection are fully explained before any experimental or clinical treatment begins.^{1,2} By definition, confidentiality refers to information that has been communicated in trust of confidence, such that disclosure would, or could, incur particular prejudice and harm. In research and practice settings, confidentiality involves the management of private information based upon a respect for the person who is the subject/patient.³

The intent of maintaining confidentiality is to afford protection of subjects/patients from the harms of stigma, potential embarrassment, socio-economic manifestations, and illicit use of information.⁴ But while the autonomy of persons and their freedom to have and maintain privacy and secrecy must be respected, the philosopher Sissela Bok maintains that such respect for autonomy must equally recognize that secrets can be disclosed and shared as personal choice.⁵ In this way, while the researchers' and clinicians' obligation to respect and provide subjects'/patients' confidentiality is binding, it is also dependent upon each person's desire and "right" to share information.⁶

It could be assumed that anonymity and confidentiality would be desired. Yet, certain subjects/patients might refute such 'protection' and thus their expressed non-confidentiality (e.g.-

disclosure of participant identity and information) would need to be respected, realistically considered, and perhaps complied with. This can be problematic and generates a number of questions. For example, if we assume a priori that subjects/patients deserve anonymity and confidentiality, then are we actually acting paternalistically and impugning participants' autonomy (i.e.- the negative right of refusal—in this case, their refusal of privacy) if and when we prohibit and/or restrict participants' opportunity to reveal personal identification? Should subjects and patients be free to disclose their identity as a matter of choice—and clinicians and researchers prohibited from restricting such disclosure—even if it negatively impacts the conduct of clinical care and/or the medical fiduciary?

Choice And Autonomy

So, if we address the notion of autonomy as relevant to persons' freedom to whatever extent of privacy and secrecy they choose, then what of those situations in which the patients/subjects explicitly desire to waive the provision of confidentiality, and seek to be identified as participant in a particular research study or clinical treatment? To re-iterate, this scenario is becoming increasingly more common, as subjects view such identification as a way of "giving voice" to their personal experience (of a disorder, situation, etc.) or a cause, serving as an example to others, feeling empowered, finding 'value' by offering their opinions (and identity), and/or engaging their voice and identity as a marketable commodity.

In this way, individuals may wish to be identified, and may even feel that they have a 'right' to be identified if they so wish (viz. Bok's autonomy⁷). If this were the case, then by making decisions about confidentiality on behalf of the subjects/patients, researchers and clinicians would be acting paternalistically and further reinforcing the imbalance of power by implying that the imperatives of non-disclosure outweigh the autonomy and 'rights' of the subjects.⁸

So, we might be prompted to question the value of enforcing absolute confidentiality. An underlying logic is that if researchers/clinicians can trust their subjects/patients to make an informed choice to consent to taking part in research and/or treatment, wouldn't it be logical to assume that these same subjects/patients could also make informed choices about whether or not to waive their confidentiality? In this way, as Bok has noted, latitude to defer confidentiality might be afforded as circumstantially and ethically appropriate. Still, given the multitude of clinical situations and the richness of ethical issues that

arise from them, the decision to offer subjects/patients a ‘choice’ as to whether or not to waive confidentiality may not simply be a contingency of informed consent.⁹

The Risks And Challenges Of Identity Disclosure

Given that both research and clinical practice are interactions between moral agents (i.e.- moral enterprises) and therefore dictate ethical conduct, then affording subjects’/patients’ confidentiality can be derived from the maxim of beneficent intent in that it presumably reduces the potential for harm.¹⁰ A fundamental issue is the potential risks posed by the loss of confidentiality and the disclosure of personal and clinically relevant information. Certainly, patients would need to be informed of these potential risks. But would this be sufficient in those situations in which subjects’/patients’ decisions to defer confidentiality were made in an emotional state? And if the emotional reaction toward the study or treatment (and its results and outcomes) were to change, such change in emotions and attitudes could have significant impact upon what and how subjects/patients describe their care, and interpret its benefit(s). So, some mechanisms would need to be in place to allow a progressive assessment of patients’ confidentiality decisions. But is this really feasible or possible?

Subjects/patients would need to understand the durability of potential effects once their identity appears in print. Despite the best intentions and most stringent attempts to limit where and how patient information could be revealed and directed, once in the public domain there can never be complete certainty about where the dissemination process could lead and in what context(s) patient information could be accessed, seen, and used. Subjects’ reaction to such use of information may instigate litigious actions and so safeguards would need to be developed to address this issue—to protect both patients and researchers/clinicians.¹¹

Consequences of waived confidentiality would need to be directly addressed and discussed—not merely assumed. A potential solution would be to insure that when subjects choose to defer confidentiality, they do not, and cannot, subordinate the autonomy of others and/or place the confidentiality of others at risk. But while this process might ensure the opportunity to thoroughly discuss this issue, it can be very time-consuming and may increase the potential for (additional) pragmatic burdens and ethical concerns.

One of the ethical issues created by waived confidentiality is the resultant strain upon the medical fiduciary.^{12,13} Subjects/patients may not be aware of, or in agreement with, the interpretations of clinical results and findings and so deferred confidentiality may incur situations in which there is the possibility for categorical argument(s) about the ‘meaning’ of outcomes, data, etc. This may be reinforced by market-model values. If subjects feel that they have some stake-holder affirmation that is linked to their disclosed identity, then conflicts of value (and meaning) may easily arise.¹⁴

So, the issue is based upon the question of whether or not enforced (i.e.- mandatory or assumed) confidentiality is ethically problematic—or whether it is at least less problematic than offering patients a choice to waive confidentiality. Within this debate, there are certain practical issues that must be addressed. At the core, some consensus needs to be reached as to whether the option of waiving confidentiality is even viable.

The Limitations and Limits of Autonomy

Perhaps the issue is reducible to an appreciation of both the limitations incurred by respect for (both patients’ and clinicians’) autonomy and the limits of autonomy as a guiding principle. It is important to recall that respect for autonomy is not ‘absolute’ and can be subordinated to other moral obligations in real-world situations.¹⁵ The extent that subjects/patients are made ‘vulnerable’ by the asymmetry of knowledge and power in the medical relationship and/or those relationships that impinge upon it (e.g.- market circumstances, etc.) must be taken into accord. It may be that because of this inequality of knowledge, subjects/patients cannot appreciate certain risks and burdens and, in this way, are reliant upon the knowledge, wisdom, and discretion of the clinician when making decisions relevant to clinical care. This prompts the question of whether subjects/patients can truly apprehend and negotiate the potential implications of waiving confidentiality. If subjects/patients may not recognize their relative incapacity to predict or understand the

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implications and ramifications that disclosing identity and details of treatment effects may incur (to themselves and the system of medical care), then we must assess whether the obligation to respect subjects’ autonomous choice to defer confidentiality would not be better over-ridden by: (1) the somewhat weakly paternalistic aforementioned concerns of the researcher and clinician, and/or (2) justifiable, yet more strongly paternalistic, frank enforcement of confidentiality.¹⁶ If these questions were addressed through guidelines that support confidentiality as a subject-dependent choice, any such guidelines would need to present a clear process of consent that fully explains the possibilities and consequences of deferring confidentiality—many of which are non-proximate, unintended, and undesirable.¹⁷

But the more pressing question is whether offering subjects such freedom to defer confidentiality creates explicit tensions of “trumping autonomies.”¹⁸ On one hand, the autonomy of researchers/clinicians to limit or deny subjects/patients the negative right to refuse confidentiality may be seen as a (paternalistic) trumping of subjects’/patients’ autonomy. On the other hand, accommodating subjects’/patients’ right to refuse confidentiality may threaten researchers’ and clinicians’ autonomy to act in accordance with their role-values and thus might affect the rigor of the study, treatment or, in some cases, the probity and professional integrity of medical practice. In this latter regard, we must acknowledge the effects of market forces on the use of disclosed identity (and aspects of clinical care) as advertisement.

Ultimately, we must bear in mind that medicine (and the research that supports it) remains a moral enterprise and, within this enterprise, subjects/patients must be regarded as ends unto themselves and not merely means. Researchers and clinicians are obligated to respect the choices of those in their charge and care but must also recognize the responsibility, as stewards of knowledge, to conduct such care (whether in experimental or clinical settings) in ways that are morally sound—as both an individual and public good.¹⁹ Thus, while options may be avail-

able to allow subjects/patients particular latitude in participatory choices regarding their non-confidentiality,²⁰ the practicality, ethical value, and durable impact of any and all of these options upon the conduct and fiduciary of medicine must be carefully considered. ■

Acknowledgements

This work was adapted from Giordano J, O'Reilly M, Taylor H, Dogra N. "Confidentiality and anonymity: The challenges of offering research participants the choice of disclosing their identity" published in *Qualitative Health Research*, 2007. The authors thank Dr. Michelle O'Reilly and Helen Taylor for their contributions to both the research and work in the former projects and to our ongoing studies.

James Giordano, PhD is Samueli-Rockefeller Professor of Medicine and Neurosciences, and Scholar-in-Residence at the Center for Clinical Bioethics, Georgetown University Medical Center, Washington, DC, and is Director of the Center for Brain, Mind, and Healing Research at the Samueli Institute, Alexandria, VA. He is a Visiting Fellow in Medical Philosophy and Neuroethics at Harris Manchester College, University of Oxford, UK.

Nisha Dogra, MD, PhD is a pediatric psychiatrist and is Senior Lecturer in Child and Adolescent Psychiatry in the Department of Health Science, Children's Division of Psychiatry, Greenwood Institute of Child Health, Leicester University, Leicester, UK, and is a Harkness Fellow in Health Care Policy.

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