

# Virtual Mentor

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## CLINICAL CASE

### Case Studies and the Therapeutic Relationship

Commentary by Ronald Pies, MD, and Judy L. Kantrowitz, PhD

Dr. Zhou is a psychiatry resident finishing her second year at an academic medical center in a university town. One of her first continuity clinic patients, Teresa, the 15-year-old-daughter of a university staff member, was referred to the clinic after her family's insurance coverage changed and she needed a new mental health provider. According to the records from her prior psychiatrist, Teresa had been diagnosed with bipolar disorder. Despite several courses of pharmacotherapy, however, she has continued to struggle with mood symptoms and is still doing poorly in school. Dr. Zhou focused her first few meetings on building a good rapport, and eventually Teresa confided in her that she had been using various drugs with her friends. Addressing substance abuse became a part of Teresa's treatment. After a year's work together, Dr. Zhou felt that Teresa had made a good amount of improvement.

When Dr. Zhou presents Teresa's progress to her attending physician, he remarks that she has been doing very well managing a complex case. Recalling that Dr. Zhou had mentioned the possibility of applying for a fellowship in child and adolescent psychiatry, he suggests that she look into writing up Teresa's case and submitting it to a professional journal. Distinguishing between bipolar disorder and substance-induced mood disorder can be very difficult even for an experienced psychiatrist, he tells her. Not only is this a good case study, he adds, but a peer-reviewed journal publication would look good on her upcoming application.

Dr. Zhou writes up the case, but returns to her attending physician, uncertain. "What are the rules about getting permission from the patient when you publish their case study?" she asks. "Just make sure you've changed her name and de-identified her," he tells her. "That's all I have usually had to do." Her other clinical mentor disagrees. "Lots of the journals are changing their policies," she says, "and many of them would expect you to ask Teresa and maybe her parents for their consent, then have them read the draft over before you send it in." Dr. Zhou is concerned about how she should proceed. She doesn't think Teresa would necessarily mind being written about, but she wonders if that information will change her dynamic with the patient.

### Commentary 1

by Ronald Pies, MD

Clinicians have been writing about their patients (or clients) for more than a century. Indeed, Sigmund Freud maintained that psychoanalysts have an affirmative *duty* to

publish what they learn from treating patients [1]. In publishing his case history of “Dora” in 1905, Freud took several steps to conceal the patient’s identity; nevertheless, Dora’s identity was eventually discovered.

The case of “Teresa” raises many ethical questions and dilemmas with respect to publication of clinical case reports. What are the physician’s fiduciary responsibilities to the patient? How should physicians weigh their duty to protect the patient’s privacy against their well-recognized responsibility to share their clinical experience and to educate colleagues? If physicians routinely seek the patient’s permission to publish case studies, must they also allow patients the “right to revise or reject” the case write-up? How do the specific concerns in treating children and adolescents affect these decisions?

### **General Ethical Implications of Case Reports**

Among the many ethical considerations in publishing clinical cases are the following: (1) preserving *confidentiality*—that is, protecting the patient’s right to privacy; (2) fulfilling the physician’s *pedagogical responsibilities*; (3) adhering to the principle of nonmaleficence, which entails avoiding any action that may harm the patient; and (4) respecting the potential *ownership rights* of the patient to written material that pertains to his or her care [2].

In truth, it is not clear precisely what clinical material physicians are required to keep “confidential.” On the one hand, *information contained in the medical record belongs to the patient* and, absent a subpoena or other compelling legal authorization, cannot be released to third parties who are not directly involved in the patient’s care without the patient’s explicit consent [2, 3]. On the other hand, it is not clear that physicians are ethically required to subject written accounts *of their own clinical experiences* to a “prior restraint” process governed by the patient’s preferences. Thus, the *physician’s narrative*—whether a case study, an essay, or a poem—is arguably the intellectual or artistic work product *of the physician*. In this view, so long as adequate measures are taken to disguise the identity of the patient, the physician has no obligation to obtain the patient’s permission to publish the case material. Indeed, any putative “right” of the patient to approve or edit such material creates potential barriers to the unfettered transmission of medical knowledge. Nonetheless, the principle of nonmaleficence may impose certain constraints on what the physician may publish, sometimes superseding the physician’s pedagogical responsibilities and prerogatives [2, 3].

### **Risks to the Therapeutic Alliance**

One can easily understand, in this age of Google and Facebook, that some patients may seek out and discover professional articles written by their physicians. A patient who recognizes himself or herself in the physician’s case report may react with anger, dismay, or confusion if not adequately prepared for this event. Some medical writers will seek more informal “assent” on the patient’s part, without going through a formal consent procedure. I have generally published case material relating to *former* patients treated many years ago without attempting to “track them down” or

obtain informed consent in such cases. Not all colleagues would agree with this approach, and omitting informed consent clearly raises the threshold for disguising the case material and protecting the patient's confidentiality.

Finally, even though the patient's informed consent may protect the author and the journal, it may fail to protect the patient from an adverse outcome if, for example, a reader is able to identify the patient from the written report and uses this information against the patient's interests. Clearly, such an outcome could be devastating to the therapeutic alliance and could create serious legal problems for the physician.

### **Is Obtaining Informed Consent Always in the Patient's Best Interest?**

Notwithstanding such risks, one perspective argues that the very act of obtaining the patient's permission to publish may sometimes be harmful—and even unethical. With respect to patients still in treatment, Levine and Stagno [4] argue that asking the patient's permission to publish *crosses a professional boundary*; i.e., it inappropriately inserts the doctor's personal and professional agenda into the patient's treatment. Dealing with the physician's agenda may consume the patient's time and energy, and, on this view, risks transforming a treatment session into an adversarial discussion of the physician's personal or professional goals.

Furthermore, the very concept of informed consent may be dubious when it comes to obtaining a patient's consent to publish. After all, a patient in treatment might reason, "If I don't give Dr. Jones permission to write up my case, she might not like me anymore—maybe she'll even stop seeing me." Given the asymmetric power relationship in the patient-physician dyad, the notion of truly informed consent—freely and autonomously provided—is at least open to question.

### **Journal Policies on Case Reports**

The editorial policies of professional journals reflect a wide range of concern about privacy in clinical case reports [4]. For example, one prominent journal, the *American Journal of Psychiatry*, has a very succinct and generalized requirement, under the rubric of "patient anonymity":

Ethical and legal considerations require careful attention to the protection of a patient's anonymity in case reports and elsewhere. Identifying information such as names, initials, hospital numbers, and dates must be avoided. Also, authors should disguise identifying information when discussing patients' characteristics and personal history [5].

In recent years, however, there has been a trend toward more stringent consent requirements, as typified by these instructions from the *British Journal of Psychiatry*:

If an individual is described, his or her consent must be obtained and submitted with the manuscript.... The individual should read the

report before submission. Where the individual is not able to give informed consent, it should be obtained from a legal representative or other authorized person. If it is not possible for informed consent to be obtained, the report can be published only if all details that would enable any reader (including the individual or anyone else) to identify the person are omitted [6].

Interestingly, these instructions seem to require that *even the subject of the case report* should not be able to recognize him- or herself in the report. One wonders how far the clinician would need to depart from the salient clinical facts of the case to disguise it even from the patient. Furthermore, radical alteration of the clinical data runs the risk of weakening or confusing the relevant teaching points. Nonetheless, self-recognition on the patient's part—even if not technically a violation of the patient's privacy—presents substantial risks to the therapeutic alliance.

### **Specific Issues for Dr. Zhou**

In the case at hand, there are also ethical and legal issues arising from the patient's status as a minor. As forensic psychiatrist Robert Simon has noted, confidentiality statutes may distinguish between “young minors” and “emancipated minors”; i.e., minors aged 14 or older may be considered “emancipated” when they are not living at home or are self-supporting [7]. In general, the parents or legal guardians are the legal decision makers for young minors. This may not apply in the case of emancipated or “mature” minors, who may be deemed sufficiently mature to consent to treatment—and, by extension, to publication of case material. How Dr. Zhou should proceed in the case of “Teresa” may depend, in part, on the formal or informal understanding Dr. Zhou has with the patient and her parents (see below).

Finally, Dr. Zhou has to consider her motives in publishing Teresa's case history. These bear on the physician's responsibility to put the patient's needs first, under the rubric of beneficence and nonmaleficence. For example, Dr. Zhou might do well to reflect on whether her desire to publish represents a legitimate wish to educate colleagues or a more self-focused need to “please” her attending physician or secure her entrance into the fellowship program. Of course, most ambitious physicians want to advance their careers, as well as win the approval of their supervisors and teachers. These feelings *per se* should not preclude publication of a case—but they may merit a process of reflection, introspection, and consultation with supervisors or colleagues.

### **What Should Dr. Zhou Do?**

In my view, there is no single “right” answer to this question. Given Teresa's age and the ongoing nature of treatment, I would be inclined to obtain both Teresa's permission and that of her parents. However, my opinion might differ if Dr. Zhou had worked out a clear understanding or therapeutic contract with Teresa and her parents, stipulating otherwise. For example, some mature or emancipated minors might not want to have any communication with parents, a preference the physician

should honor except when there is a question of “danger to self or others,” e.g., in the event the (minor) patient became suicidal. When such an understanding exists, the patient herself would be presumed competent to consent to publication. Clearly, it is important for physicians to work out a therapeutic contract with their patients regarding publication of case material—though I suspect this is rarely done. It is especially important in cases involving the treatment of younger or nonemancipated minors.

### **Conclusion**

Determining the best approach in Teresa’s case is indeed a difficult judgment call, and it behooves the physician intent on publishing case reports to plan ahead for similar contingencies. In situations where possible harm to the patient or to the therapeutic alliance appears to outweigh the “teaching value” of the case report, the physician may be obligated to withhold publication entirely. As this is a complex, highly subjective determination, consultation with a senior colleague or supervisor may help the physician reach a more objective decision.

Alternatively, some physicians may choose to *collaborate* with patients in writing up the case report, as was suggested by psychiatrist Michael A. Schwartz in a personal communication in 2007. Of course, as he pointed out, this collaborative model poses its own set of problems, e.g., what to do when the patient wants to delete material that the physician wishes to include. Other physicians intent on publishing clinical cases might consider an informed-consent process at or near the beginning of treatment. This would apprise the patient of the physician’s usual policies regarding case reports and allow the patient to express concerns or even to “opt out” of the writing project. This sort of consent procedure must convey to the patient that the physician’s care and treatment will in no way be jeopardized if the patient chooses *not* to be the subject of any case reports.

Perhaps, then, we are left with this open-ended assessment by psychiatrist Glen Gabbard:

No approach [to publishing case material] is without its problems. A clinically based decision must be made in each case regarding whether the best strategy is to use thick disguise; to ask the patient’s consent; to limit the clinical illustration to process data without biographical details...or to use composites [8].

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### **Commentary 2**

**by Judy L. Kantrowitz, PhD**

Although Dr. Zhou's mentors disagree about whether it is necessary to ask Teresa's consent, as professionals they would agree that when clinical material is published it must be written in such a way that people reading the account are unable to identify the patient. But how can the author be sure? What kinds of disguise can the writer provide to maintain the relevant facts of the case while concealing the patient's identity? In this instance, the patient is an adolescent, and it is likely that her age is relevant to her difficulties. So changing her age in any dramatic fashion would distort the material; it could only be altered slightly. What about a change in gender? We would have to know more of the details of the case to determine whether such a change would or would not distort the report. Could Dr. Zhou change the particular substance that Teresa uses? Maybe. Again it would depend on details we don't know. So what other ways of disguising are possible? She could alter details of history that are not pertinent to this patient's difficulties, such as her parents' professions, her number of siblings, whether there is a family history of bipolar illness and, if so, which relative suffered from this problem.

The point is that Dr. Zhou must be sure that the disguise she uses really protects her patient's confidentiality—that others reading the article won't recognize her. Dr. Zhou's mentors would agree on this. I hope that neither of her mentors would allow

someone who was new at writing about patients to decide what degree of disguise was adequate. But what level of de-identification would keep the patient herself from recognizing her own story? The patient is a teenager and unlikely to read the psychiatric literature, but she will grow up and might be curious. Also, in this instance, one of her parents is a university staff member, someone who, depending on the field, might read a psychiatric journal. In addition, now that published articles are likely to be available on the Internet, they are available to the public and, specifically, to patients and their families as never before. Any curious patient can simply enter a therapist's name, find out what he or she has written, and most likely view the article.

The author needs, therefore, to ask herself how Teresa would feel if she read this. Can Dr. Zhou write the case in such a way that her patient (or her patient's parents) could read it years later and think, "That sounds like me, but I'm not sure it is. Could she have had another patient with a similar problem?"

In addition to the issues of disguise, clinicians must be careful, respectful, and sensitive in what they write about their patients, and how they do it; describing the patient in a manner that makes her feel like a specimen or otherwise demeaned must be avoided. How would Teresa feel reading about herself? Would she feel misrepresented? Objectified?

### **Does Writing Change the Treatment Dynamic?**

Dr. Zhou thinks that Teresa wouldn't necessarily mind being written about, but she wonders how asking for permission might change the dynamic in the treatment. Her concern about the effect of asking permission is well-founded and indicates her sensitivity as a clinician. Patients often grant this permission. They want to please their therapists, and some understand the importance to the field of disseminating knowledge through publications. Because their granting permission is influenced by the relationship and transference to their doctor, it can never be viewed as fully autonomous consent.

In this case, the patient is not an adult and may not be aware of how she will feel about her case being in print when she is older. Consent should be asked of her parents as well. If, however, they were to read what Dr. Zhou writes, as her mentor suggests, Teresa's confidentiality would no longer be preserved.

How will knowing her doctor is writing about her affect their therapeutic relationship? It is unpredictable, but there will most likely be some effect. If Dr. Zhou's request is granted, she will need to be alert to signs of reaction, e.g., a change in the patient's openness or her mood, negative feelings, or apparent criticisms of other adults that might actually have to do with her feelings about Dr. Zhou. Teresa's feelings about being written about and their effect on the treatment itself need to be explored. Is that workable? It depends on the patient, therapist, their relationship, and their ability to talk openly together about what Teresa thinks and feels.

Teresa might only react later. For example, I asked a patient if I might use a childhood experience of hers to illustrate a point in a paper I was giving. She reflected on the possible ramifications and then gave consent. A year later, she asked me to write a recommendation for her that would require my providing a dynamic diagnostic assessment. I tried to analyze her wish for me to do this, the meaning to her of what she imagined I would write, and so on. Ultimately it was clear to her that this was not something I would do, since I believed it would interfere with her treatment. “So,” she said, “it’s fine for you to write about me when it’s in your interest, but not when I believe it is in my interest.” While we were able to work out this therapeutic tangle, her reactions alerted me to be aware that consent may well be much more complex than it seems at first.

Informed consent is never fully informed because the meaning of having given it may not be fully conscious and it may change over time. A patient may think he or she really likes the idea of being written about; it makes him or her feel special and specially connected with the therapist who asks this permission, but the sense of specialness may come to interfere with other aspects of the patient-physician relationship.

### **Patient-Vetted Literature?**

Stepping back from the individual patient-physician dyad, there is the broader danger that, should informed consent become the accepted standard for publication, all subsequent literature would be patient-vetted. A literature that depended on patient approval would be skewed, inasmuch as clinicians would avoid addressing issues, such as negative countertransference reactions, that they wouldn’t want patients to be privy to. Exclusion of such topics from the literature could lead therapists to believe these areas did not exist for others or, at the least, should not be acknowledged publicly.

Given all these potential difficulties, why should Dr. Zhou write about Teresa? If her attending physician is correct that she has done therapeutic work that can help distinguish bipolar disorder from substance-induced mood disorder, she has a contribution to make to the literature. A field that lacks an up-to-date literature will stagnate. We need the enrichment that comes from peer-reviewed articles. Published papers are also an important and necessary way of preserving a history of any given field.

Therapist-authors wear two hats. First they are clinicians who have promised to do no harm, but they are also professionals who are committed to keeping intellectual discourse and ideas vibrant and relevant in their field. These two roles may sometimes conflict with each other.

In the course of working on my book, *Writing About Patients: Responsibilities, Risks, and Ramifications* (2006), I interviewed 141 clinicians about their attitudes and practices when writing about patients and 37 patients about the effect of reading about themselves. From these interviews, I concluded that there is no single or

simple solution to the problem. Applying strict guidelines to all situations does not make clinical sense. There are potential clinical consequences both when therapists ask their patients' consent and have them read what they have written and when patients discover and read publications about them without having been informed. The ethical principle that guides the decision is "do no harm." But what is harm is not always predictable.

If Dr. Zhou wishes to write about Teresa, who is not old enough to fully understand the implications of granting consent, involving her parents in the decision making will necessarily compromise her confidentiality and may jeopardize Teresa's trust and the therapeutic relationship. If Dr. Zhou does not ask permission and uses only disguise, how likely is it that Teresa will be recognizable to herself or her parents if they read the paper? If Teresa does recognize herself, can she talk openly and honestly with Dr. Zhou about her reactions? Has Dr. Zhou considered how she would respond? How it might affect the treatment? If she decides to ask permission, is she ready to accept a refusal? If Teresa or her family wish her to alter or omit parts of what she has written, would she be willing to do so or not pursue publication?

There are no clear answers, only self-scrutiny, seeking consultation, and using one's judgment.

### **Conclusion**

Since Teresa is a minor and parental consent would be needed, confidentiality would be broken. Such a breach of confidentiality could jeopardize her treatment. Therefore, unless Dr. Zhou can find a way to adequately disguise her patient so she feels reasonably sure that neither Teresa nor her parents will recognize themselves, I believe she should not publish this case.

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