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Auto/Biographical, Biomedical, and Ethnographic Ethics

Because everyone "has" a memoir, we all have a stake in how such stories are told. For we do not, after all, simply have experience; we are entrusted with it. We must do something—make something—with it.

—Patricia Hampl, I Could Tell You Stories

Language can never contain a whole person, so every act of writing a person’s life is inevitably a violation.

—Ruthellen Josselson, Ethics and Process in the Narrative Study of Lives

The democracy or, to put it differently, the catholicity of life writing—its accessibility to "nobodies" (even, in Philippe Lejeune’s phrase, "those who do not write") relative to other literary genres—engages subjects who may be especially vulnerable to misrepresentation and exploitation. Today, people with disadvantaging or stigmatizing conditions are increasingly visible in life writing, and those who represent them must take care not to override their interests or over-write their stories. For ethical guidance with life writing projects, especially those involving vulnerable subjects, we may look to the disciplines of bioethics and anthropology.

Biomedicine may seem an odd source for ethical principles pertinent to life writing, for two reasons. First, medicine is a professional field, like law and journalism, and as we have seen, professional ethical codes can be parochial and self-serving. Consider, for example, the notion of "professional courtesy" as preferential treatment for colleagues and hence, in effect, discrimination among clients. But "biomedical ethics" has always meant more than "physician ethics" or even "clinical ethics," and today, as biomedicine attempts to grapple with unprecedented problems and procedures, that is truer than ever. In any case, biomedical ethics is perhaps the most highly developed version of normative ethics available today. Further, according to Tom L. Beauchamp and James F. Childress, the authors of the standard text on the subject, "the common morality contains a set of moral norms that includes principles that are basic for biomedical ethics" (12). If this is correct, then biomedical ethics represents not a set of narrow ethical principles arising from the practice of medicine but rather the invocation in clinical and biomedical contexts of broader, if not universal, principles.

A second reason why biomedicine may seem an odd repository of life writing ethics is that one may not think of it as a site of much life writing, except for the highly specialized clinical genre of the case history (which has generally been ignored as life writing, a neglect I address in chapter 5). A more obvious source would be the social sciences, among which anthropology has been the most concerned with life writing, especially in the form of the ethnographic life history. In fact, anthropology's ethical guidelines are pertinent and useful, and will be invoked later. But because biomedicine involves relationships based on trust, and because patients are by definition vulnerable subjects, biomedical ethics is particularly pertinent to the sorts of circumstances that interest me. Perhaps because of its literally life-and-death concerns, biomedical ethics offers a particularly comprehensive account of ethical principles and reasoning. (And it is doubly pertinent when life writing involves quality-of-life issues, as is commonly—indeed, increasingly—the case. This question will be explored especially in chapter 6 on euthanography.)

Ethical scrutiny is most urgent with regard to subjects who are disadvantaged, disempowered, or marginalized with respect to their partners or collaborators. Beauchamp and Childress's characterization of doctor-patient relations helps to define the sorts of life writing relationships that concern me most: "Both law and medical tradition distinguish the practice of medicine from business practices that rest on contracts and marketplace relationships. The patient-physician relationship is founded on trust and confidence; and the physician is therefore necessarily a trustee for the patient's medical welfare. This model of fidelity relies more on values of loyalty and trust than merely on being true to one's word" (312). Although Jeffrey MacDonald would seem hardly a "vulnerable" subject—except perhaps in his apparent naïveté (which may be the flip side
of his narcissism)—any judgment of the ethics of Joe McGinniss would depend in part on the nature of his relationship with MacDonald. And that in turn depends on what one considers the ultimate basis of their partnership, the contractual arrangements made prior to their collaboration or the friendship that developed (or seemed to) during the course of their close contact during MacDonald’s seven-week trial. If McGinniss was bound only by the letter of their legal-commercial agreement, then his behavior was proper; if he was bound by the spirit of the trust they seemed to share, then his deception of MacDonald appears ethically problematic.

As Edmund D. Pellegrino and David C. Thomasma point out in a discussion of fidelity to trust in medicine, “trust is most problematic when we are in states of special dependence—in illness, old age, or infancy or when we are in need of healing, justice, spiritual help, or learning. This is the situation in our relationships with the professions that circumstances force us to trust” (65). With life writing, as with some professional practices, persons in states of dependency—such as disability, illiteracy, institutionalization, legal minority, incompetence, or terminal illness—often depend on agents more powerful or privileged than themselves to hear, articulate, and act on their stories. (Death would not seem to qualify as a state of dependence; indeed, it might seem to suggest utter invulnerability to harm; but I would argue that it entails maximum vulnerability to posthumous misrepresentation because it precludes self-defense. Thus, we trust that after we die our corpse will be treated with respect, that our “will” will be honored, and that secrets we may have divulged will be respected, either by being kept or by being communicated only to certain parties or in certain ways. In this regard, death may be the state of ultimate vulnerability and dependency.)

But although journalists, doctors, and lawyers may at times function as life writers, journalism, law, and medicine are professions in a way that life writing is not; even for professional biographers, life writing has no official or even consensual professional ethics. Outside the professions, then, with life writing there is no protection for vulnerable subjects in the form of “system trust”: trust in the procedures of education, licensing, accreditation, and supervision (Pellegrino and Thomasma 66–67).

As agents, proxies, or collaborators, life writers are rarely selected on the basis of credentials; more often they are chosen (or they nominate themselves, a crucial difference) on the basis of emotional intimacy or relational proximity. The very basis of their qualification—their intimate relationship to their subjects—may reflect their trustworthiness, but when it does not, it places those subjects at high risk of betrayal. Thus, intimacy itself entails a degree of vulnerability.

In life writing scenarios involving particularly vulnerable subjects, such as children, members of disadvantaged minorities, and people with certain kinds of illnesses and disabilities, even when partnerships are formalized, life writing collaborations may be thought of as fiduciary relationships, that is, relationships of trust akin to those between physicians and patients, in which “the benefit to one party is maximized by leaving that party vulnerable to being taken advantage of by the other” (Mehlman 27). (Maxwell J. Mehlman explains this paradox as follows: “The fewer the resources the patient expends to verify the physician’s good faith, the more vulnerable the patient is to the risk that the physician will betray the trust” [36n45].) So, too, vulnerable subjects may be inclined and encouraged to rely wholly on trust in their collaborators. In any case, when the relationships between vulnerable subjects and their life writers are roughly analogous to those between patients and physicians, in that the latter have privileged access to and implicit power over the former, then the principles of biomedical ethics may be an appropriate resource for guidance. In what follows, I suggest how these principles may be adapted to inform our consideration of the ethics of life writing.

All four of the major principles of biomedicine that have been virtually canonized—the so-called Georgetown mantra—in the successive editions of the standard text, Beauchamp and Childress’s Principles of Biomedical Ethics—respect for autonomy, nonmaleficence, beneficence, and justice—seem pertinent to life writing, and all may come into play in different ways. (And as in bioethics, these principles represent only prima facie obligations; that is, they are binding only when no conflicting obligations override them. Thus, they are not absolute and inflexible.) But my focus here is on the relevance of the first three to life writing involving vulnerable subjects. The scenarios examined in this section are generally fiduciary ones. In such relationships, partners whose preexisting characteristics or conditions put them in dependent positions to begin with are at higher-than-usual risk for the exposure inherent in all life writing. (We should not let the acknowledgment of vulnerability in some subjects obscure the fact that even in relationships of unequally powerful partners,
each depends on the other for the completion of the project. And we should be alert to ways in which supposedly vulnerable subjects may assert power and agency greater than might be expected.

A primary principle of ethical representation of vulnerable subjects should be respect for autonomy, which is rooted in a fundamental ethical principle, respect for persons: "Kant argued that respect for autonomy flows from the recognition that all persons have unconditional worth, each having the capacity to determine his or her own moral destiny. To violate a person’s autonomy is to treat that person merely as a means, that is, in accordance with others’ goals without regard to that person’s own goals" (Beauchamp and Childress 63– 64). The term “autonomy,” whose etymological meaning is “self-rule” or “self-law,” is a complex and contested one. To begin with, in reference to individuals, the term has several distinct but related meanings: “The capacity to govern oneself, which of course is a matter of degree; . . . the actual condition of self-government and its associated virtues; . . . an ideal of character derived from that conception; or (on the analogy to a political state) . . . the sovereign authority to govern oneself, which is absolute within one’s own moral boundaries” (Feinberg, Harm 28). Thus, it can apply to the supposed ability of an individual to make meaningful decisions, a particular individual’s possession of that ability, the right to make such decisions, or the circumstances under which an individual is granted the power to do so. In addition, the notion of autonomy as a character trait has been justly critiqued as reflecting a questionable (and patriarchal) view of individuals as atomistic. As Maeva Cooke has noted, feminists have been concerned that the idea of autonomy as a core cultural value may represent a narrowly gendered and not altogether healthy ideal, since it characterizes the subject as “disembedded,” or even disembodied, ignoring the relational and contextual dimensions (258– 60).

Believing that ethics requires a notion of autonomy, however, Cooke has suggested that autonomy can be salvaged from its historical interpretations by retaining the ideals of agency, responsibility, accountability, and intentionality while rejecting the notion of selves as atomistic and self-originating. She stresses that individual autonomy cannot flourish under conditions of economic, social, or political oppression (264– 69). Hence the principle of autonomy is inseparable from that of justice, broadly conceived. In any case, there is an important distinction between regarding autonomy as an individual characteristic and as a right to be protected, as a capacity to be assumed in competent persons and as a capacity to be nurtured in the vulnerable.

My concern here is mainly with autonomy as a right. Later, in my consideration of ethical cases, especially those involving some form of surrogacy, I will be concerned with autonomy as a transpersonal phenomenon, a capacity not to be found in totally independent individuals but one that is to be exercised within relationships of interdependency. Indeed, many ethical dilemmas involve our awareness of just those dimensions of the self.

The following statement of the principle of respect for autonomy as a right, devised for biomedical settings, seems to me adaptable to life writing: “The principle . . . includes the right to decide as far as possible what will happen to one’s person—to one’s body, to information about one’s life, to one’s secrets, and the like” (Beauchamp and Childress 297). (As I have suggested, in life writing this principle may extend beyond the death of the subject.) By analogy I would argue that, ideally, the subjects of life writing should have the opportunity to exercise some degree of control over what happens to their stories, including secrets and private information. Thus, over-writing their stories—imposing an alien shape on them—would constitute a violation of their autonomy, an overriding of their rights, an appropriation of their literary, moral, and economic property. This principle, however, has to be adapted to different scenarios and the genres characteristic of them. Thus, for example, the subject of an as-told-to autobiography deserves far more consideration and control over the narrative than the subject of an intimate biography, who in turn deserves more consideration than someone who is a secondary or minor character in a memoir or autobiography. The ethical stakes are proportionate to the centrality (and vulnerability) of the figure involved and the intimacy and interdependence between the writer and the subject. The writer’s dependence on the subject is proportionate to her need for the subject’s cooperation in the form of, say, extended interviews or privileged access; the subject’s dependence may be manifest in incapacitating conditions that preclude self-representation or self-defense against misrepresentation.

As Adam Zachary Newton has pointed out, “getting someone else’s story is also a way of losing the person as ‘real,’ as ‘what he is; it is a way of appropriating or allegorizing that endangers both intimacy and ethical duty . . . .” One’s responsibility consists of responding to just this paradox” (19). In a biomedical context, one justification of the reduction of personal narratives to medical histories, of persons to patients, is that it serves therapeutic ends. This may be viewed, from a consequentialist viewpoint, as a matter of the end justifying the means, and, from a deon-
tological (duty-based) viewpoint, of favoring the principle of beneficence—doing good—over that of respect for autonomy.

A similar justification might be offered of much social science research that involves vulnerable human subjects: that it benefits them—or others like them (an important distinction and a weaker justification). The potential harms of life writing are more akin to those of social research than to those of biomedicine; the former are not likely to cause physical injury or death, as medical treatment too often does. But whether and how the representation of vulnerable subjects in life writing benefits them is also less clear than with medicine; hence the need for ethical scrutiny.

The psychologist Terri Apter has reflected on unforeseen responses in her work with adolescent girls:

One 16-year-old felt that her words had been “stolen”: “I see how you got what you said. I’m not saying it’s wrong, but when you read about yourself . . . Well, it’s me, but not me. It’s really weird.”

Like other psychologists, I would defend my procedures on the grounds that good comes from them, too. The changes in perspective that may be forced on people who read about themselves in someone’s rendition of their self-narratives can be enlightening and validating. (31; emphasis added)

That is, Apter argues that the initial sense of self-alienation, violation, or appropriation experienced by her subject might be outweighed by the benefit of the enlightenment or validation it forces on her—an appeal to the principle of beneficence. Any inquiry into life writing ethics has to acknowledge that life writing can do good for or to its subjects, whether they seek it or not. Yet, as in medicine, such paternalistic rationales can be self-serving: note Apter’s acknowledgment of force, and note that the hypothetical benefits she cites were not the purpose of the research.

Although the use of composite, altered, or pseudonymically veiled portraits in much biomedical or social science research shields subjects from being recognized by others, it does not protect them from the shock of self-recognition. Thus, the ethics of life writing collaborations can be tricky even when the subject is anonymous. One of Ruthellen Josselson’s subjects responded to a disguised portrait of her by seeking to revise it, not because she felt Josselson had misunderstood or misrepresented her but because she felt she had misrepresented herself: “What she had found in my report was what she felt was a dishonest version of herself, and this only increased her shame about the part of herself she regards as a black spot on her soul. My written account reminded her of the ways in which she hides from the world. Her stifled narcissistic rage at having participated in my study was about seeing in the textual mirror the ‘false self’ she presents to the world” (“On Writing” 69).

In this case, while the original report remained unrevised, the dynamics of the collaboration became much more complex, as the subject, in a meta-confessional gesture, responded to her veiled public representation by revising her private confidence—and perhaps achieving a new level of self-knowledge. The process of representation became recursive and reflexive to an unexpected and extraordinary degree. Josselson’s terms—“dishonest,” “shame,” “narcissistic rage”—suggest how high the stakes can be for the subject, how emotionally and ethically fraught such interactions can become. At the same time, even as the vulnerable subject speaks back to and revises her representation, she is dependent on Josselson to validate her self-image.

Josselson concludes with a revealing confession of her own.

I have taken myself out of relationship with my participants (with whom, during the interview, I was in intimate relationship) to be in relationship with my readers. I have, in a sense, been talking about them behind their backs and doing so publicly. Where in the interview I had been responsive to them, now I am using their lives in the service of something else, for my own purposes, to show something to others. I am guilty about being an intruder and then, to some extent, a betrayer. (70)

This statement nicely isolates one ethical crux: how the life writer negotiates between a primary relationship with a subject (which involves self-representation to that subject, usually in person and often over a long period of time) and a secondary relationship with readers (which involves a very different sort of self-representation to a very different sort of audience through a very different medium). A host of ethical problems may spring from the divergence between the axes of these relationships and from the displacement of the earlier intimate relationship by the later, distant one. The danger of making one’s subjects instrumental to one’s own purposes is also clear.

Josselson does not see herself as betraying her subjects by misleading them (as McGinniss misled MacDonald); betrayal comes with her abandonment of them, her eventual privileging of her relation with anonymous readers over her prior intimate relation to them. It is a violation not of confidence or privacy but rather of intimacy which she regrets as inherent in her trade. Like Malcolm and other journalists, she does not for-
swear what she sees as an act of questionable ethicality; she calls rather for a candid and open acknowledgment of its ethical problematic: "Doing narrative research is an ethically complex undertaking, but I do not advocate that we stop doing it. Rather, I am suggesting here that although this is important work, it is work we must do in anguish" (70). This is of course easy for her to say since it requires mostly a change in consciousness, which is not accessible to inspection, rather than in behavior, which is. Still, the value of such an acknowledgment is considerable, for it supports scrutiny of behavior and of textual products.

The ethical burden of life writing can also be expressed more positively and open-endedly:

The other does not simply exist; it imposes responsibilities, obligations, constraints, regulations: it claims its rights. . . Have we attended to the voice, the face, the law, of the other? Have we been faithful to its dictates? Have we permitted the other to be itself, to retain its autonomy? Have we taken proper care, proper responsibility? The answers to such questions form the content of ethical self-awareness. (Harpham 7)

Such self-awareness—that is, acknowledgment of the face and the autonomy of the other even, or especially, when the relationship is consensual—is a characteristic of the most ethically responsible life writing. It is a matter not just of responsibility but of responsiveness. The challenge is to enact or communicate this on the page.

Autonomy is best respected when subjects are granted some control over their stories; this is not inconsistent with what would otherwise be violations of privacy. On the contrary, in this regard the subject of life writing is analogous with the patient:

When individuals voluntarily grant others some form of access to themselves, their act is an exercise of the right to privacy, not a waiver of that right. For example, our decision to grant a physician access for diagnostic, prognostic, and therapeutic procedures is an exercise of our right to control access that includes the right to grant as well as to exclude access [whether to the body or to the mind]. . . . In these instances, we exercise the right to privacy by reducing privacy in order to achieve other goals. (Beauchamp and Childress 297)

The agreement of a subject to confide in a collaborator or life writer, then, is not carte blanche, not a waiver of privacy rights, but rather a will-ing sacrifice of privacy with the goal and expectation of some compensatory benefit. Ethical partnerships, then, especially with vulnerable subjects, would involve respect for the integrity of their stories and for their rights—both authorial and economic—to their own stories. That is, like other collaborators or consensual partners, subjects should have some degree of control over the shape their stories take and, in some cases, an opportunity to share the proceeds from the sale of their stories. Or, if they cede these rights, they should do so only with "informed consent."

Vulnerable subjects are more likely to have their autonomy violated in practice precisely because what makes them vulnerable—whether their extreme youth or age or their physical or mental impairment—may be thought inconsistent with their autonomy; those perceived to have diminished autonomy are often, for that reason, treated in a way that may reduce whatever autonomy they do have. There is a further danger. In some cases, such as those of limited mental capacity or cognition, the very cause of subjects' vulnerability to exploitation may seem to make them invulnerable to certain kinds of harm—such as psychic pain or harm to reputation. (For example, if subjects—Iris Murdoch, for example—are incapable of reading the texts their cooperation or collaboration makes possible, they may be considered beyond being harmed by them.) Ironically, then, the assumption of their invulnerability to harm may make them all the more prone to abuse. Thus, in scenarios involving vulnerable subjects, a kind of legalistic "respect for autonomy" is not always adequate, for that vulnerability affects how their autonomy may be exercised.

The following passage, which expresses an ethical obligation in medicine, might also serve to articulate an ethical ideal in life writing: "Such respect [of doctor for patient] involves respectful action, not merely a respectful attitude. It also requires more than noninterference in others' personal affairs. It includes, at least in some contexts, obligations to build up or maintain others' capacities for autonomous choice while helping to allay fears and other conditions that destroy or disrupt their autonomous actions" (Beauchamp and Childress 63). Here Beauchamp and Childress recognize that the assumption that individuals are autonomous is not always valid—even among "competent" persons—and that the principle of respect for autonomy requires more than passive, legalistic noninterference. It is not paternalistic to intervene in order to realize or maximize a patient's, or subject's, potential for autonomy. Life writing that is ethically ideal, then, might involve optimizing the autonomy of subjects, not merely "respecting" it.
In medicine, one manifestation of respect for autonomy is the principle of informed consent, which is formalized, quite reductively, in various ways including written permission; medical procedures are authorized only when consent is freely given by an adequately informed, competent patient (Beauchamp and Childress 81). Similar standards apply to all "research involving human subjects"—regardless of discipline—which is governed by uniform protocols and reviewed by institutional review boards (IRBs). Such standards originated with the Nuremberg trials following World War II; the trials of Nazi doctors, who had experimented on unwilling subjects, gave rise to the Nuremberg Code of conditions that distinguish ethical research on human subjects. These in turn inspired codes adopted by the National Institute of Health in 1953 and the Department of Health, Education, and Welfare in 1974 (Shea 28). According to these codes, consenting subjects must be informed of the "risks" and "benefits" of the project, and of their right to withdraw from it.

So, too, I would say, with life writing collaborations, especially those involving vulnerable subjects: they should be apprised ahead of time of the risks and benefits of the project and of their right to withdraw at any point under certain conditions. By benefits, I mean not only the presumed benefits to them, among which the primary one may be the unquantifiable but nevertheless significant value of having their stories told—or even merely listened to—but also the possible benefits to their collaborators and intended benefits to the public. Thus, sources or subjects should be aware of the possibility that others may profit from their stories in tangible or intangible ways. The knowledge that others may profit materially from access to their stories may alert them to mercenary motives in their collaborators and thus protect against economic exploitation. In effect, then, respect for autonomy should include respect for the person not just as "other" but also as a source of literary property with potential market value. As a variant or ramification of the Kantian principle that "one must act to treat every person as an end and never as a means only" (qtd. in Beauchamp and Childress 351), perhaps we can say that, although we have the right to commodify ourselves, we do not have the right to commodify others without their knowledge and permission.

In my ethical calculus, the rights of subjects to proceed from and control over the text vary with the magnitude of their role in the text and the degree of their involvement in its production—their labor, their time, their granting of access to self and personal information—and with its format, whether biographical ("The Story of X") or autobiographical ("X's Story"). At the same time, the possibility that a wider public may benefit immaterially from subjects' stories may endow cooperation with a desirable and hitherto unsuspected altruistic motive (as when a story of victimization may help to prevent the abuse of others). I am not suggesting, then, that subjects must always be materially rewarded for their stories or their cooperation. They may be sufficiently gratified to know that their otherwise untold stories might have value in the marketplace; thus, the awareness of the potential profit to the writer may provide "psychic income" to the subject.

We cannot expect nor could we require of nonprofessional life writers the sorts of certification that researchers in the medical and social sciences—and even the humanities—are obliged to submit when engaged in research with human subjects. But, in addition to being consensual, their relations with subjects should be characterized by a property I call transactional visibility (or accessibility), which obtains when the partnership's terms and implications are made available for inspection by subjects and, ideally, by consumers of any resulting text. I deliberately avoid the term "contractual," since equitable arrangements can be achieved without written contracts, and as we have already seen, such contracts by no means guarantee equity and justice. (Note, however, that the accessibility of these arrangements to vulnerable subjects can be diminished or compromised by precisely those conditions that render such subjects vulnerable in the first place.) Collaborative transactions too often remain invisible and inaccessible to readers; the arrangements, the negotiations that led to them, and the distribution of proceeds generally occur behind the scenes. Even when they are described or enacted in the narrative, such representations are far from transparent—especially since they are usually controlled by one party. With all of those considerable qualifications, I favor and strongly encourage the inclusion in collaborative narratives of accounts of the transactions and negotiations that produced them—what Paul John Eakin calls "the story of the story." At the very least, this puts on record an account that is subject to verification or challenge by concerned parties.

Some circumstances, such as institutionalization, and some conditions, especially mental illnesses, may compromise, limit, or abrogate autonomy; thus, although all subjects are entitled to respect as persons, not all subjects have autonomy, and the nature of the collaboration—and whether it is in fact permissible—must depend in part on the competence of the subject. In some cases, then, respect for persons will mean honor-
ing autonomous choices, whether they seem wise or not; in others, as noted earlier, it may mean intervening to augment or maximize autonomy where there is some question; in yet others, it may mean recognizing a lack of autonomy sufficient to permit meaningful consent.

In medical contexts, when patients are incompetent, the principle of respect for autonomy is honored by seeking an appropriate decision-making surrogate, according to one or more standards. According to the standard of “pure autonomy,” the decision is to be guided by the patient’s previously expressed wishes or values, as conveyed by directives such as “living wills” (Beauchamp and Childress 99–100). According to the “substituted judgment standard,” a surrogate is asked to make the decision the incompetent person “would have made” if competent. (This requires someone who knows the patient well and has no conflict of interest.) According to the “best interests” standard, the surrogate is to decide which among competing actions or decisions in best overall for the patient, regardless of whether the patient would have made that choice under the circumstances (Beauchamp and Childress 102). This last standard is generally used with children, who may be thought of as not yet having achieved autonomy or having lived long enough to supply meaningful evidence of their ideals and values. Beauchamp and Childress refer to the second of these standards as involving “ghostly autonomy,” but that phrase applies more loosely to all of them, since all involve a sort of “ghostwriting” of the life script by a surrogate author (100). These distinctions may help us to parse and resolve the sorts of ethical dilemmas that crop up in life writing collaborations with less than fully autonomous subjects, many of which involve “ghostwriting” not just in the narrowest sense of that term (unacknowledged authorship). That is, these standards may help us assess the conduct of those who write about or for others who are unable to cooperate in a very active or self-protective way, such as subjects with cognitive or psychiatric impairments. Since collaborative writing with, or on behalf of, vulnerable subjects necessarily involves surrogacy, biomedical ethics is a useful reference for analysis and evaluation of such partnerships.

The biomedical principles of nonmaleficence and beneficence are also pertinent to life writing collaborations or partnerships involving vulnerable subjects. Rather than differentiating sharply between these princi-

ples, Beauchamp and Childress distinguish among obligations to prevent harm or evil, to remove harm or evil, and to do or promote good (115). This seems a useful approach for life writing ethics as well, especially if we recognize the distinction between ordinary and extraordinary moral standards. According to Beauchamp and Childress:

The first level [of obligation] is limited to standards in the common morality that pertain to everyone. These standards form the moral minimum. They include obligations specified in moral principles and rules, as well as the virtues that we expect all moral agents to possess. . . . The second level is a morality of aspiration in which individuals adopt moral ideals that do not hold for everyone. . . . Other persons can praise and admire those who fulfill these ideals, but they cannot blame or criticize those who do not pursue them. Persons who do not accept these ideals are not bound by them and cannot be criticized for not adopting them. (39–40)

In a biomedical context, of course, beneficence is obligatory; it is, after all, the raison d’être of the profession: “Promoting the welfare of patients—not merely avoiding harm—expresses medicine’s goal, rationale, and justification” (Beauchamp and Childress 173). In life writing, by contrast, beneficence represents an extraordinary standard, at most an ideal rather than an obligation. (We do not expect, and we should not require, biographers to act on behalf of and in the interests of their subjects.) Nevertheless, the principle of beneficence may help us to assess the goals and effects of certain life writing projects. And the rules that are obligatory in biomedicine may be desirable in life writing involving vulnerable subjects: “1. Protect and defend the rights of others. 2. Prevent harm from occurring to others. 3. Remove conditions that will cause harm to others. 4. Help persons with disabilities” (Beauchamp and Childress 167). These rules may be especially pertinent with regard to life writing subjects undergoing biomedical procedures or institutionalized in medical or rehabilitative institutions, as is frequently the case today (as in the work of Oliver Sacks, explored in chapter 5).

Beneficence is also pertinent when life writing partnerships, as suggested earlier, constitute fiduciary relationships akin to that between physician and patient. Such relationships, Beauchamp and Childress argue, involve special ethical standards: “When a patient contracts with a physician for services, the latter assumes a role-specific obligation of beneficent treatment that would not be present apart from the relationship” (175). Similarly, when writers team up with vulnerable subjects,
whether contractually or not, such collaboration entails role-specific obligations. While any partnership—including those between previously unacquainted individuals (like McGinnis and MacDonald)—involves such role-specific obligations, many life writing scenarios involve cooperation with partners who are already embedded in “special moral relationships,” such as familial ones (like the Hampfs, mother and daughter). In such relationships, the preexisting intimacy raises the stakes, since it creates special liability to exposure and harm. Although it may be unrealistic and inappropriate to require writers to do good to their subjects—and difficult to know how to define and measure that good—it may be proper to expect that writers at least do no harm to consenting vulnerable subjects.

Thus far, I have been invoking biomedical ethics in the form of the somewhat abstract “principilism” of Beauchamp and Childress; at this point, however, I turn to a passage in which they depart from principilism to invoke the ethics of care:

The ethics of care maintains that many human relationships (e.g., in health care and research) involve persons who are vulnerable, dependent, ill, and frail and that the desirable moral response is attached attentiveness to needs, not detached respect for rights. Feeling for and being immersed in the other person establish vital aspects of the moral relationship. Accordingly, this approach features responsibilities and forms of empathy that a rights-based account may ignore in the attempt to protect persons from invasion by others. (373)

The more intimate the preexisting or collaborative relationship between writer and subject—the more history they have together—the more pertinent the ethics of care is to their life writing partnership, and the more the partners are bound by something greater than mere “detached respect for rights.”

Beauchamp and Childress make two further distinctions pertinent to the issue of nonmaleficence. While they define “harm” nonnormatively or nonprejudicially as “thwarting, defeating, or setting back some party’s interests,” they make a distinction critical to life writing ethics, that between justified and unjustified harm:

A harmful action by one party may not be wrong or unjustified on balance, although acts of harming in general are prima facie wrong. The reason for their prima facie wrongness is precisely that they do set back the interests of the persons affected. Harmful actions that involve justifiable setbacks to another’s interests are, of course, not wrong. They include cases of justified criminal punishment, justified demotion of an employee for poor performance in a job, and discipline in schools. (116–17)

Thus, in the McGinnis-MacDonald case one could concede that McGinnis had “harmed” MacDonald—by destroying any residual credibility and reputation and undermining his protestations of innocence—but argue that such “harm” was justified by his apparent responsibility for the heinous murder of his family and his stunning lack of remorse.

In this case, the justification would go beyond the defense against libel—that the account was true—to suggest that MacDonald deserved to be exposed as narcissistic. That is, the effect of McGinnis’s book may not have been beneficial to MacDonald, but it was to the public and his wife’s family, removing doubt as to the justice of the verdict and perhaps shedding some light on the genesis of the crime. (In this case, the principle of “justice,” which in biomedical ethics usually has to do with the distribution or allocation of scarce resources, would seem to correspond more closely with its conventional legal usage: McGinnis’s biographical verdict on MacDonald reinforced the jury’s. Justice was done.) Similarly, the exposure of an abuser in a memoir by a victim of child or spouse abuse would qualify as justified harm.

The notion of harm can cover many different sorts of injury relevant to life writing:

Some definitions of harm are so broad that they include setbacks to interests in reputation, property, privacy, and liberty. So broad is the term harm in some writings that it seems to embrace almost every condition that might restrict autonomous action, such as causing discomfort, humiliation, offense, and annoyance. Such a broad conception distinguishes trivial harms from serious harms by the magnitude of the interests affected. (117)

Of course, if we were to adopt a notion of harm so broad that any life writing that caused “discomfort, humiliation, offense, and annoyance” was considered unethical, we would be adopting an inappropriately restrictive standard. Regarding the relations between journalists and their subjects, Janet Malcolm has rightly said: “Journalists who swallow the subject’s account whole and publish it are not journalists but publicists. If the lesson of MacDonald v. McGinnis were taken to heart by prospective subjects, it could indeed, as [McGinnis’s lawyer] maintained, be the
end of journalism" (144). Similarly, if life writing were considered unethical whenever it caused its subjects any sort of discomfort or pain, it would be the end of life writing as we know it. But we should remember that the issue is not whether harm is caused but of what kind or order (trivial or serious), and whether any such harm is justified. For me the key factor is the degree of vulnerability of the subjects. The more vulnerable the subjects (the less capable of protecting themselves), the more scrupulous life writers must be about avoiding gratuitously harmful representations of them.

A second useful distinction that Beauchamp and Childress make is that between harming and wronging, where harming means adversely affecting someone’s interests, while “wronging involves violating someone’s rights. . . . [H]arming need not involve such a violation, or a wrong, or an injustice. To see this distinction, consider that people are harmed without being wronged in circumstances of attack by disease, acts of God, bad luck, and acts by others to which the harmed person has consented” (116).

To rephrase an earlier assessment of the MacDonald-McGinniss relationship, one might concede that while McGinniss had harmed MacDonald, he did not wrong him, insofar as MacDonald’s written release constituted consent to McGinniss’s act (though one could also argue that McGinniss had wronged as well as harmed MacDonald by violating a trust that transcended a contractual agreement). The point is that whether life writing is ethical or not is not a simple matter of whether it causes harm to its subject; instead the question is whether and how that harm may be justified, and whether it constitutes wrong.

To sum up, I have argued that an approach to the ethics of life writing might look to biomedical ethics for guidance because biomedical ethics today provides a particularly comprehensive account of normative ethics, because life writing partnerships sometimes resemble the sorts of confidential fiduciary relationships that exist between physicians and patients, and also because in some cases the narratives themselves recount scenarios in which more narrowly biomedical issues are the subject. One needs to keep in mind, however, the difference between ethical obligations and ethical ideals, so as not to be hypercritical of life writers.

Although biomedical ethics may be more comprehensive and systematic than anthropological ethics, anthropology is probably the discipline in which life writing has received the most rigorous ethical scrutiny, so it is apt that the ethics of ethnography might also be called upon in formulating an approach to the ethics of life writing, especially when life writing focuses on the “other.” Anthropology provides a helpful supplement to the principles of biomedical ethics for two reasons. The first is that its ethical principles and practices have been devised to operate (generally) outside of clinical contexts, which is where most life writing is located. The second is that whereas biomedical ethics tends to focus on one subject at a time, too often in isolation from social, historical, and cultural contexts, anthropology is oriented to communities. According to David M. Fetterman, the ethnographer’s ethical code “specifies first and foremost that the ethnographer do no harm to people or the community under study. . . . [T]he ethnographer is careful not to trample the feelings of the natives or desecrate what the culture calls sacred” (120). With the statement that the first principle is the avoidance of harm, we can see the congruence between medical and anthropological ethics, and in fact, there is considerable overlap between the ethical concerns of anthropology and some of medicine; anthropology’s concerns with permission (consent), honesty (disclosure), trust (confidence), privacy, and reciprocity (mutual benefit) are also characteristic, as we have seen, of biomedical ethics (Fetterman 130–35). But with the emphasis on respect for the community, we find a dimension lacking in most accounts of biomedical ethics: an overt consideration—indeed, a favoring—of social units rather than mere individual subjects.

Anthropological ethics reminds us that harm can be done to communities as well as to individuals, a realization absent from, or late coming to, most other academic fields. When life writing has to do with individuals rendered vulnerable by some marginalizing condition, one ethical concern should be with the effect of the project on the community to which such individuals belong—or perhaps to which they may be assigned. Thus, George Rosenwald, a psychologist, reminds us that research that devalues a group can inflict damage on members of that group; there is no protective membrane between individuals and the communities to which they belong:

The Ethical Standards ([of the American Psychological Association], 1953) protect individuals only against damage and only against damage inflicted directly and pointedly. On this ethical view, the study of ethnic and gender group differences continues to flourish in human psychology despite the fact that, in addressing issues of social concern, it inevitably produces odious comparisons—odious differences, odious inequalities. Because there
is nothing in the Standards to prevent injuring a tolerant individual through the depreciation of his or her group, there is also little impetus for researchers to exercise their ingenuity in the devising of research that would be beneficial to the groups about whom they are concerned. (258–59)

Increasingly, just as medical patients and disabled people have begun speaking back to physicians and challenging medical narratives about their conditions, members of minority groups are talking back to the social sciences. Sally McBeth, co-author of the life story of an elderly mixed-blood Shoshone woman, notes that “American Indian people no longer tolerate the intrusions of social scientists into their lives without some guarantee that they will not only see the final research project, but also have some control over it. They don’t allow anthropologists to conduct research that is not of value to them, that resists their own perception of themselves, or that perpetrates [sic] stereotypes” (153). Through a process of self-examination on the part of social scientists and self-assertion on the part of historically marginalized subjects and groups, the principles and practice of life writing have been subtly but significantly changed.

James Clifford has concisely appraised the predicament of ethnography at the turn of the millennium in ways that are relevant to the representation of vulnerable subjects generally, especially those who are members of distinct communities:

The writing and reading of ethnography are overdetermined by forces ultimately beyond the control of either an author or an interpretive community. These contingencies—of language, rhetoric, power, and history—must now be openly confronted in the process of writing. They can no longer be evaded. . . . [T]here is no liberation . . . in recognizing that no one can write about others any longer as if they were discrete objects or texts? (“Partial Truths” 25)

One of the reasons why it is no longer possible—or at least permissible—to objectify others is that those “others” have begun to challenge the cultural, political, and ethical authority of that objectification. As Caroline Brettell notes, one of the factors contributing to anthropology’s searching self-examination in the last quarter of the twentieth century was the new phenomenon of ethnography being read and critiqued by its subjects (2–3). For some vulnerable subjects, of course, speaking back is difficult, if not impossible. Notable, however, among hitherto marginalized groups that have begun to respond to their representation, textual or extratex-

tual, by others are people with disabilities, both as individuals and as a community. Indeed, Carol Thomas defines disability as a social construct in terms of the harm it does: “Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being” (3).

What is at stake in the ethics of life writing is the representation of the self and of the other, which is always at once a mimetic and a political act. In the chapters that follow, I invoke principles and distinctions I have introduced here in order to bring to life writing the sort of ethical scrutiny I think it demands and deserves. I use the word “invoke” deliberately. The scenarios that concern me are located neither in the domain of biomedicine nor in that of ethnography but rather in some gray area—but not a no-man’s-land—between or adjacent to them. The systematic application of biomedical or ethnographic ethical concepts to these life writing projects would be both tedious and inappropriate. Moreover, as the principles are invoked in particular cases, they may need to be adapted and adjusted. At most, they will serve as guidelines or reference points rather than as rigid rules.

Life writing is far too complex and variable to be subjected to a set of abstract, unvarying, and presumably universal principles. Interesting cases may require the revision, amplification, or qualification of principles, or the invocation of alternative ethical approaches such as the ethics of care. Even though the principles invoked may prove finally inadequate, then, their invocation may be illuminating. Thus, I see the relation between ethical approaches and cases not as a matter of deductive, one-way application but as a recursive and dialectical interaction. Such interaction—the mutual illumination of cases and ethical concepts—may help us negotiate between the two poles represented by the epigraphs to this chapter. Ruthellen Josselson reminds us that the act of writing another’s life is inherently partial and thus inadequate, presumptuous, and possibly transgressive. By contrast, Patricia Hampl reminds us of the imperative to make something, through narrative, of the experience—others’ as well as our own—with which we are entrusted.