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Consent and Money

A dialogue on the ethical dilemmas in the reporting and writing of The Immortal Life of Henrietta Lacks

By Sue Ellen Christian and Ann Miles

There are, essentially, two issues to deal with: consent and money.
— Rebecca Skloot, *The Immortal Life of Henrietta Lacks*.[1]

Introduction

More than 50 years ago, as Henrietta Lacks lay unconscious in a hospital operating room in Baltimore, cells from her cancerous cervix were removed—not as part of her treatment, but to be cultured for medical research. While her cells, known today as HeLa, continue to flourish in petri dishes around the world, Lacks died of her cancer shortly thereafter. Her story, a tragic one of poverty and early death, is told by Rebecca Skloot in her bestselling book *The Immortal Life of Henrietta Lacks*, published in 2010. In the book, we learn about how the cells were taken from Lacks, the importance of this cell line to scientific research, and how the Lacks family has responded to the knowledge that her cells live on in perpetuity. The cells were sliced from Lacks's cancerous cervix without her knowledge or consent and the Lacks family has never profited from them. HeLa cells grow at an astonishing rate, a rate

Sue Ellen Christian is an associate professor of journalism at Western Michigan University. Her book, *Overcoming Bias: A Journalist's Guide to Culture and Context* was published in 2012 by Holcomb Hathaway. Ann Miles, Ph.D., is a cultural anthropologist. She is the author of *From Cuenca to Queens: An Anthropological Story of Transnational Migration* and *Living with Lupus: Women and Chronic Illness in Ecuador*, both from the University of Texas Press.

that has propelled scientific research, research profits, and the notoriety of the cell line.

Skloot reminds us, however, that these are not anonymous cells. They come with a family name and a history and they are genetically connected to living, breathing, human beings. For example, when German researchers in March sequenced and published online the genome of the cells, they were, in essence, also publishing the genome of Henrietta Lacks's remaining family. The medical future of Lacks's descendants, while admittedly a future based on inferences, was published without their consent and for all to decipher. The National Institutes of Health (NIH) met with the Lacks family in response to that article and to a genome analysis of a HeLa strain of cells that was pending publication. In August 2013, the NIH announced an historic agreement with the descendants of Lacks to store the HeLa cell genome data in their database and allow for only controlled access to it.[2]

Because of the ethical issues the book raises and the debates and responses it initiated, in the fall of 2012 Western Michigan University selected *The Immortal Life of Henrietta Lacks* as its campus-wide book read. More than 150 colleges, universities and high schools have done the same.[3] The common read designation invites students, faculty, staff, and administrators to read the same book and attend or host discussions about it. The WMU discussion included a panel on the ethical issues raised in *Immortal Life*. The audience seemed primed for a discussion of the scientific ethics at the heart of the Lacks story; that is, should her cells have been taken in the first place and do people have "rights," financial and otherwise, over our cells and tissues? However, the panelists focused not on the ethics of science and the behaviors of scientists who were long dead, but rather on something that seemed to make some in the audience a bit more uncomfortable: Skloot's reportorial and research ethics.

The following essay, situated as an exchange between two scholars who were on that original WMU panel, invites readers to consider another tale told by *The Immortal Life*: the story of ethical choices made not by powerful medical professionals or biotech companies but rather in the reporting, research, and writing of the book. This story is embedded in the book itself. Our aim is to help readers of any nonfiction work appreciate the critical decisions that Skloot as a journalist faced and the issues this present discussion raises: How far is too far? What justifies the means to an end? And most valuably, what can we learn from *Immortal Life* to inform our understanding of nonfiction texts? Our alternating viewpoints, one of a journalist and one of an anthropologist, analyze Skloot's processes of

gathering information and interviewing sources—processes that inherently involve power and choices. We explore Skloot's choices: the intimate family details she includes, her decision to insert herself into the narrative, and the promise to share the monetary proceeds from book sales or appearances with the Lacks's family via a foundation. Skloot takes on the enormous responsibility of telling a complicated, important story about one patient. We aim to bring to the fore those responsibilities and the way Skloot manages them.

Anthropological and Journalistic Perspectives

> *This is a work of nonfiction. No names have been changed, no characters invented, no events fabricated. While writing this book, I conducted more than a thousand hours of interviews with family and friends of Henrietta Lacks, as well as with lawyers, ethicists, scientists, and journalists who've written about the Lacks family.* — Immortal Life*, xiii.*

Sue Ellen Christian

I frame my critique of Skloot's book around professional ethical codes because Skloot herself references her ethical challenges and she identifies herself as a journalist. As a former staff writer at a large metropolitan news organization, I read *Immortal Life* with journalistic ethical guidelines in mind. Would I make the same decisions were I in Rebecca Skloot's place? What alternatives did Skloot have when building a working relationship with Henrietta Lacks's daughter, Deborah Lacks, who becomes a de facto reporting partner in the book? What can students learn from these decisions? How to balance the means with the end result? This book has raised important questions for me as a journalist and journalism educator.

The Society of Professional Journalists has four main directives, one of them being to act independently as a journalist.[4] This directive includes avoiding conflicts of interest, remaining free of associations and activities that may compromise integrity or damage credibility, and disclosing unavoidable conflicts. Another highly regarded set of journalistic principles was developed by the Committee of Concerned Journalists in 1997 and became the basis for the 2001 book (since revised) *The Elements of Journalism* by Bill Kovach and Tom

Rosenstiel. One of the nine principles is that "journalists must maintain an independence from those they cover." The principle states:

> Independence is an underlying requirement of journalism, a cornerstone of its reliability. Independence of spirit and mind, rather than neutrality, is the principle journalists must keep in focus. While editorialists and commentators are not neutral, the source of their credibility is still their accuracy, intellectual fairness and ability to inform—not their devotion to a certain group or outcome. In our independence, however, we must avoid any tendency to stray into arrogance, elitism, isolation or nihilism.[5]

Appropriately, early in her book, Skloot is forthright that she and Deborah grew up in very different cultures. "I grew up white and agnostic in the Pacific Northwest, my roots half New York Jew and half Midwestern Protestant; Deborah was a deeply religious black Christian from the South."[6] These two very different women join forces for some amazing reporting excursions. Journalistic accounts do not typically refer to "we" when deciding what part of the reporting comes next, but Skloot involved Deborah Lacks at every stage. She says she had to in order for Lacks to continue working with her. Skloot promised to take her on her reporting visits and to share information she uncovered about Henrietta Lacks.[7] This is highly unusual because of the concern that a source will unduly affect the story's telling, or will bias the coverage toward the source's point of view instead of a more rounded point of view. The depth of their partnership often challenges the journalistic ethic of independence. And we don't learn much about Skloot as a character in Deborah Lacks's story, though Skloot describes herself as such. She gets to make that choice because she is in control of the story and the publication. However, if Skloot did not acknowledge her involved role in Deborah Lacks's life, she'd be on equally thin ethical ground, for a lack of transparency and honesty. To me, the compromises throughout this text are what make it so rich for discussion in collegiate journalism courses.

It is no coincidence that scholars have drawn parallels between anthropology and journalism; the similarities are one of the delightful discoveries I made after leaving full-time journalism for academia, as both fields are immersed in observing the stories and cultures of people who are often very different than the practitioners. Journalists serve as filters of events. We decide what is news and what isn't; that is surely a form of power. Again, journalistic codes of ethics acknowledge that power, and caution against abusing it through guidelines that include a prohibition against paying news sources that have a vested interest in a story.[8]

Skloot chronicles the rough history that the Lacks family had with journalists and media coverage, including by *Rolling Stone* magazine and the BBC. Skloot also vividly details how poor the family was, how in need they were of basic medical care and insurance coverage. We know from a quote from Deborah Lacks's second ex-husband, Reverend James Pullum, that money was important to the family. "They want to be assured that they going to get some MONETARY SATISFACTION," he tells Skloot when he finally picks up one of Skloot's many unanswered calls to their home.[9] Deborah was concerned about money and whether Skloot was being paid by Johns Hopkins or some other entity to do research and write the book. "Each time I told her the same thing: I hadn't sold the book yet, so at that point I was paying for my research with student loans and credit cards. And regardless, I couldn't pay her for her story. Instead, I said, if the book ever got published, I would set up a scholarship fund for the descendants of Henrietta Lacks."[10] Indeed she set up the Henrietta Lacks Foundation and donates a portion of her book proceeds to it. The foundation, as of June 6, 2013 had awarded 43 grants: 31 for tuition or books, 10 for medical or dental aid, and two for emergency needs. The foundation's purpose is to "provide financial assistance to needy individuals who have made important contributions to scientific research without personally benefiting from those contributions, particularly those used in research without their knowledge or consent."[11]

As a reader, I find Skloot's approach to helping the Lackses profit from their story innovative, laudable and appropriate. But the reportorial instinct to "follow the money," as journalists are taught to do, leaves me wondering about how Skloot's promise to create a fund may have influenced the family's cooperation. While the money is richly deserved by Henrietta Lacks's descendants, Skloot is investing the family in a financial way in *her* project. Her offer to set up a fund ties the monetary reward to her reporting and writing success.

Ann Miles

My perspective on reading *Immortal Life* stems primarily from my profession as a cultural anthropologist, one who has written for 25 years about the lives of the socially marginal in modernizing Ecuador. In reading this book I found myself as interested in how the author discusses the processes of research and text construction as I was in the facts surrounding Henrietta Lacks's cells or the lives of the Lacks family today. My impressions of the process

of data collection and write-up cannot be removed from my own experiences of interviewing and writing. It is from this positioned location that my concerns about the book emerge.

Since the postmodern turn in the 1980s, anthropologists and feminists have worried about the implicit power dynamics inherent in ethnographic work, including how our presence in the lives of those we study affects them and how to write about "the other" ethically. At a minimum, anthropologists understand today that they cannot leave their role as producers and purveyors of knowledge completely unexamined. It is generally agreed, however, that despite qualms about representing others and questions about how power is implicated in the research process, there is value in the writing of ethnography and of telling our "partial" truths.[12] As researchers we elect ourselves to be the "voice" of the other or the lens through which real lives are refracted, and the mere fact that we can do that is a manifestation of a kind of power. But, with power comes serious responsibility.

As a social scientist working in a university setting, my research is always subject to ethical reviews by a panel of my colleagues. Our Human Subjects Institutional Review Board (HSIRB) closely examines our research protocols with an eye towards protecting our informants or participants. Moreover, as a professional anthropologist I am guided by the ethical codes of my discipline. There is much overlap between what my institution's HSIRB requires and the American Anthropological Association's code of ethics, including how we can recruit volunteers and the importance of informed consent. There are also some important distinctions in the two sets of guidelines. While both are concerned with protecting participants from harm, the anthropological code of ethics states that "among the most serious harms that anthropologists should avoid are harms to dignity."[13] The code does not specify what "harms to dignity" means exactly, so individual researchers and writers must sort this out for themselves.

Sue Ellen Christian's concern about the monetary rewards that might come to the family vis-à-vis the Henrietta Lacks Foundation does not trouble me quite as much. While I certainly can agree that there are potential conflicts of interest, as an anthropologist I often think about how my life has been materially enriched (i.e. tenure and promotion) because I am able to publish the work that comes from interviewing people who most often are a good deal poorer than me. What do they get out of this beyond the dubious pleasure of my company? Indeed, I almost envy Skloot's ability to market the book and herself so successfully that she is able to make a profit that can actually be shared. Most academics do

not manage that. I suppose she could have kept the idea to herself until after the completion of the work, and I understand that this could be seen as an untoward inducement to participate, but my feeling is that it was the only decent thing to do. She was repeatedly asked how the family could or would benefit, and I think her response to those questions was appropriate.

Sources or Informants? The Limits of Informed Consent

> *For nearly a year after our first conversation, Deborah refused to talk to me. I traveled back and forth to Clover [Virginia] sitting on porches and walking the tobacco fields with Cliff, Cootie, and Gladys's son, Gary. I dug through archives, church basements, and the abandoned, falling-down building where Henrietta went to school. While I was on the road, I'd leave messages for Deborah every few days, hoping to convince her that if she talked to me, we could learn about Henrietta together.* — Immortal Life*, 232*.

Sue Ellen Christian

Trust is central to the reporting and writing—and even the reading—of *Immortal Life*. As a journalist, Skloot is functioning under a different set of practices and guidelines than a university researcher under an institutional review board. The rules of HSIRB do not apply to the practice of journalism, which has historically struggled with not being a licensed profession that governs itself, although at the same time, journalists pride themselves on practicing an unregulated craft. Journalists should always fully inform sources about their identity and their intention to publish. One of the ethical guidelines for journalists is to ensure that sources—particularly private citizens unversed in the ways of the news media—understand what they are agreeing to and have the ability to comprehend that their comments to a single reporter may potentially reach multitudes.

In her first conversation with Deborah Lacks, Skloot records her as saying again and again: "I can't take it anymore" and "Who are we supposed to trust now?"[14] Journalists network to find sources. A natural starting point for Skloot was gynecology professor Roland Pattillo who, in honor of Henrietta Lacks, organized a yearly conference on the HeLa cell genome at the Morehouse School of Medicine. Pattillo knew the family, had their personal contact information, and also, apparently, served as a self-appointed gatekeeper to the family. Journalists can appreciate the critical nature of such a source who has the power

to grant access to an entire phone book of family names and numbers. In these cases, a journalist seeks to build trust, prove honest intent, and establish professional credibility. Skloot accomplished all three of these aims in her three days of what she describes in her book as a "grilling" by the doctor.[15]

To gain and keep the essential source of Deborah Lacks, Skloot had to include Lacks in her reporting process in ways that journalistic ethics caution against. The critical element is that we, as the audience, know Skloot was deeply and intimately involved in their lives, and that the family—notably Deborah Lacks—was involved in her reporting. Skloot is transparent about it. She told the WMU audience that she "disclosed" this part of her reporting. She doesn't present herself as an objective, unemotional journalist. And ultimately, this keeps the reporting process honest to the source, the reporter and to us as readers.

In journalism circles, Skloot's dogged pursuit of the story is a valued trait. The depth and breadth of the story she sought often required laying groundwork. Sources may reject press coverage for a variety of reasons, from privacy to negative past experiences with reporters. Initial rejection doesn't mean a journalist gives up on a story she thinks is worth telling. Journalists may need to devote substantial time to building a relationship with sources before on-the-record conversations begin. For some stories, a journalist proceeds without key sources' blessing or involvement; the story gets told without them, through documents, public records, public events, and secondary sources. (This approach typically comes about by necessity, when journalists are reporting on the wrongdoings of someone whose best interests are not served by talking to them.) However, in the HeLa case, the wrongdoing was by physicians, not the Lacks family. Without the family's consent, Skloot would not have had access to medical records. Without access to the family, the story would have been incomplete and lack an emotional core.

Skloot strove to act ethically. For example, said Skloot during her WMU visit, she refused to pay the Lackses for their story and she bought dinner if they went out. Skloot also said she had made sure to always have her recorder running whenever she spoke with Lacks, to "remind" Lacks that she was a reporter. One day, Skloot spent hours driving with Lacks around Baltimore as Lacks sought $20 to make a car payment. "To give her the $20, I knew that was crossing the line," Skloot told the WMU audience. "I had $20 in my purse. We talked about why I couldn't give her the money."

Journalists try to infiltrate sources' lives. We do it to blend in, to get everyone used to us being around, so we can see normal life in action and chronicle it. We do it to build trust. To gain access. Or all of the above. And, yes, that may mean riding around with a source so you can fit in an interview or build rapport. The journalist should not create the scene or influence events; she should watch it unfold. I think Skloot had to constantly manage that role, and does so more successfully at some points than others. Also, Skloot is our informant about Skloot. We are left to trust her depiction of how she handled events and negotiations with the Lacks family. What is her alternative to this role? I don't think she had good options—who else will depict her role? But it is, I think, appropriate for readers to be aware of the one-sided nature of the telling.

Ann Miles

Those of us in academic settings are told both within our disciplinary ethics committees and by our respective institutions that subjects have the right to refuse to be interviewed or participate in any way in our research projects. Depending on the composition and inclinations of an institution's HSIRB, researchers are given a range of directives concerning how we can recruit subjects, what we can say to them to encourage participation, and how we will protect participants' rights, including those of privacy and confidentiality, throughout the research process. Participation in research, it is stressed, must always be inarguably voluntary. While the word "voluntary" is open to interpretation, the explicit understanding, I suppose, is that no one should ever be coerced in any way to participate in a research project, and the implicit understanding is that we must always respect the individual's right to refuse to participate.

Skloot as an independent writer had no such institutional oversight. Skloot's identity as a journalist is asserted throughout the text, mostly in her repeated claims about her doggedness in getting the story. It is quite clear that while she indeed had a good deal of trouble getting the Lacks family to agree to speak with her, Skloot did not force, nor obviously coerce, the Lacks family to participate. Indeed, over time, Deborah Lacks did become very committed to the project and she came to think of Skloot as "her reporter," indicating a connection that many an ethnographer would envy.

Yet, there remains much that troubles me and it starts at the very beginning. As Sue Ellen Christian points out, Skloot first contacted Deborah Lacks, her entrée to the family,

through a cold-call after obtaining her phone number from Roland Pattillo, a physician who organized a symposium on Henrietta Lacks's cells and who knew the family personally. Skloot claimed she was "grilled" by Pattillo, who was hesitant to give her the number, thus leaving us to believe she passed all the necessary tests to have access to Deborah Lacks's personal phone number. Skloot reports that Pattillo told her, "I do have the ability to put you in touch with them, but you need to answer a few questions, starting with 'Why should I?'"[16] But, is that really all it should take to obtain a phone number? Is it ethical for one "professional" to pass on a personal phone number to another without asking permission first? Pattillo clearly felt the family needed some protection, or he would not have "grilled" Skloot, but was it really his decision to make whether Skloot passed the test and if Deborah Lacks's phone number should be released? Why was Deborah Lacks not consulted first? Surely this is a privacy violation and therefore open to the same ethical scrutiny Skloot gives to other researchers and journalists who she suggests violated the Lackes's privacy.[17]

Once Skloot had Deborah Lacks's phone number, convincing her and the rest of the family to participate was not easy. After the first "manic and confusing" 45-minute phone call between Deborah Lacks and Skloot, during which Lacks seemed willing to talk, Skloot was told by Lacks in a follow-up call that the men of the family, her brothers and father, needed to approve of Skloot before she would continue talking to her.[18] Skloot writes that in that phone conversation, Lacks told her to "go away."[19] Of course she doesn't, and Skloot then chronicles many more rejections, unreturned phone calls, and missed appointments when family members stood her up. Along the way we learn about how the family was exploited in the past and why they might have been hesitant to talk with anyone about Henrietta Lacks's cells.

While Skloot's behavior may be seen as intrepid journalism, and I have no doubt that that is how she wishes us to interpret it, I see it in another light. Once an informant refuses to participate—indeed, once someone like Henrietta Lacks's husband, David, very clearly says, "leave me alone"—when, exactly, is it all right to keep pressuring them? Should we really "wear out" people until they agree?[20] When we keep insisting that others talk to us, are we fundamentally taking away their right to decide for themselves what they want? How much should researchers push people to cooperate, and when or how does persistence turn into harassment? How do we know when we've gone too far?

This leads me to ponder, to borrow a line from feminist discourses on rape, what course we embark upon when we question repeatedly if a "no" really is a "no"? Because the book spends so much time discussing and clearly critiquing issues of informed consent vis-à-vis taking Henrietta Lacks's cells, the absence of a discussion about informed consent, privacy and the right of refusal with the living members of the Lacks family presents a strange irony. Skloot does not acknowledge that informed consent, either formal or informal, is not just for biomedical research.

The Author and Subject Relationship

> *I did eventually meet Deborah, who would turn out to be one of the strongest and most resilient women I'd ever known. We'd formed a deep personal bond, and slowly, without realizing it, I'd become a character in her story, and she in mine.* — Immortal Life*, 7.*

Sue Ellen Christian

I wonder whether Skloot considered making Deborah Lacks a co-author. Skloot often references their partnership. Lacks circulated through Clover, Virginia, Henrietta Lacks's hometown, introducing Skloot—"this is my reporter." She directed Skloot to find out if the president of a cancer research foundation "was legit." As the date of Lacks's speech for that foundation approached, Skloot writes that she kept asking Lacks, "Are you sure you want to do this?" After the attacks on the World Trade Center towers, Skloot writes that "for the next several days, Deborah and I talked many times as we both struggled to make sense of the attacks."[21]

For me, Skloot's book is a rich and sometimes troubling example of the complicated contract between reporter and source—in this case, Deborah Lacks. Each journalist works out that relationship differently with key sources, particularly during a long-term project such as this one. Skloot and Lacks are truly a reporting team, with Skloot as lead reporter and guide through the complicated territory of science and scientists. However, much of that territory would remain untraveled were Lacks not a willing partner in the reporting. Skloot needs her for access to medical records and family members. So what does Deborah get? In the book, we see that Skloot gives her emotional support, a role in their fruitful search for

answers, and the promise of foundation money for Lacks descendants in need of assistance with healthcare or school bills.

Skloot wrestled with the ethics of inserting herself in the book, talking the problem over with other writers and editors. Skloot said in an interview:

> Basically my rule for first person in the book was that it's only there if it's relevant to their story. I spent so much time fighting against being in the book, thinking, "It's not my story, it's their story. It's not about me." And I was right, it's not. It's just that I became a character in their story. So many other journalists, doctors and various other people came before me in similar circumstances, wanting something from the family related to the cells. I realized I couldn't leave that out. Then there would be this obvious question: "Well, what about you?" And what happened with me was in some ways much more complicated and potentially dangerous than it was with any of the other journalists, because there was so much time together and because Deborah got so involved.[22]

Skloot's research is exhaustive and fact-checked. She is fortunate that Deborah Lacks wanted her to "tell all the Lacks story and there'll be good and bad in that cause of my brothers."[23] Often sources, like all of us, only want the positive side told. However, as Ann Miles notes later, the inclusion of some of the negative personal details seems irrelevant. The SPJ guideline states that journalists should "[r]ecognize that private people have a greater right to control information about themselves than do public officials and others who seek power, influence or attention."[24] Deborah Lacks may have wanted the whole story told, but perhaps those who appear in a more negative light did not, and we as audience do not know their wishes. Lacks can only speak for herself, not all family members.

Ann Miles

As an anthropologist who has relationships with "informants" that span decades, I know how difficult it can be to negotiate the line between the personal and the professional. I can easily see how Skloot might find herself playing multiple roles in the lives of her informants, and I am not sure it bothers me very much. My concern about Skloot's "role" has more to do with her unexamined authority in pursuing this story. Who decides that a story must be told and that, for example, Rebecca Skloot is the one to tell it? Obviously this touches on those issues of power I discussed earlier. Skloot portrays her own interest in the topic as so powerful that she would not take "no" for an answer. In fact, I had the impression throughout the book that Skloot's own interest in pursuing the topic trumped that of the

family, or perhaps even more troubling, that she felt herself to be a better arbiter than they were of their long-term interests. But here's where things get difficult.

In the end we know that the family has benefitted from the book. The HLF has been established by Skloot, and Lacks family members now go on their own speaking tours associated with the book. Never having received any financial compensation for Henrietta Lacks's cells, the family is, finally, getting some compensation from the book. For that I commend Skloot, although, despite multiple Web searches, I could not find out just how much of the profits Skloot is sharing with the family. But, the question I ask is this, and it is linked to Sue Ellen Christian's interest in following the money: If the family is, at the least, somewhat financially better off because of the book, does that mean that the ends justify the means? Knowing the benefits reaped from the book for the family, can we now look back on the process and say that Skloot was right to push the family to participate and that the anxiety, anger and risks experienced by family members along the way and recounted in the book were worth it in the end? I think many of us might agree that they were. But, in so agreeing, have we fallen into precisely the same logic that is attributed to medical science and rightly excoriated in the book? When Dr. Gey and the others took Henrietta Lacks's cells without her permission they believed that they knew best and that the ends justified the means. I am left wondering if Dr. Gey and Rebecca Skloot are more alike than different. Do they simply represent different generations of "investigators" who both believe in the power of their own good intentions? In other words, is one generation's good work another's exploitation? To be sure, the Lackses gained nothing from Gey and something from Skloot, but did not both Gey and Skloot treat the Lackses as potentially incapable of making the right decision?

These are not easy questions. I think one could logically and convincingly argue that without dogged journalists pushing sources to talk there is much we would not know that maybe we ought to know. The truth is that we cannot wait for informants to come to us, and Skloot never forced the Lackses to participate, she just kept pursuing them until they finally did. The Lackses have not, as far as I know, expressed much distress about the book or the ways it portrays their family members or Skloot's role in reporting. But serious worries remain. Skloot fails to tell us how about her own process of informed consent with the Lacks family and what we do learn is more troubling than comforting. In the end, she is silent about the implicit and asymmetrical power inherent in her dual roles as investigator

and then as de facto voice of the Lacks family. While she critiques power in others, she seemingly cannot recognize it in herself.

Skloot's Handling of Sources and the Issue of Human Dignity

> *She started frantically stuffing papers into her canvas bags as I tried to explain myself and talk her down. Suddenly she threw the bag on the bed and rushed toward me. Her hand hit my chest hard as she slammed me against the wall, knocking me breathless, my head smacking the plaster.*
>
> *"Who you working for?" she snapped. "John Hopkin?"*[25]
>
> *"What? No!" I yelled, gasping for breath. "You know I work for myself."*
>
> *"Who sent you? Who's paying you?" she yelled, her hand still holding me against the wall. "Who paid for this room?"*
>
> *"We've been through this!" I said. "Remember? Credit cards? Student loans?"*
>
> *Then, for the first time since we met, I lost my patience with Deborah. I jerked free of her grip and told her to get the fuck off me and chill the fuck out. She stood inches from me, staring wild-eyed again for what felt like minutes."* — Immortal Life*, 283–84*.

Sue Ellen Christian

Would this reporting partnership feel less ethically awkward if Skloot more fully embraced the role in which she placed herself, as a journalist deeply involved emotionally and intellectually with her key source? The emotionally charged incident quoted above is an exception; Skloot often does not reveal her emotions. Her emotional distance from the events she experiences with Deborah Lacks, who serves as the emotional engine of the book, serves to remind us as readers that Skloot is in control of both herself and the story. This sense of control for me felt both reassuring (she is maintaining the crucial distance between reporter and source; this is familiar territory) and superior (she decides what goes in the tale, including which of her emotions; this too is familiar territory, as journalists filter events through their own experiences). I wondered about her emotions and motivations at certain times. For example, when Sonny, Deborah Lacks's son, tells Skloot that his mother has died, Skloot doesn't tell us what she feels.[26]

I say this while also appreciating the lack of options Skloot has for her narrative. Were she to be more expansive about her thoughts and emotions, wouldn't she risk presenting her reactions to the HeLa story as equally significant as those of the Lacks family, and wouldn't this perpetuate a position of outsider power and further disenfranchisement of the family? As Skloot watches the faith healing that Deborah Lacks's cousin Gary performs on a distraught Deborah Lacks, she writes that she realizes Lacks is burdened by the knowledge of what happened to her mother and her cells. "As I watched, all I could think of was, Oh my God . . . I did this to her."[27] Skloot implies a two-way emotional connection that would understandably and perhaps inevitably affect a reporter's presentation of information, but Skloot ends at only implication instead of exposition. For me as a reader, this gave me pause. Did I want to know more about Skloot's struggle in the peculiar journalist/source relationship she was in? Was it enough to know that the relationship was deep and complicated?

Another aspect of Skloot's unusual role in her own book is that she was not only a character, but was an educator as well. The family asked Skloot to guide them through the thicket of science about the HeLa cells so they could understand what happened to Henrietta Lacks and her tissue, and to Henrietta's older daughter, Elsie. They invited her to be their guide. The Reverend James Pullum, Deborah Lacks's second ex-husband, when introducing Skloot to the congregation said, "I was very angry with Sister Rebecca when she started calling us. So was my wife. Then finally we said okay, but we told her, 'You need to talk to us like we're regular folk. You need to tell us what's goin on.'"[28] The Lacks family was really Skloot's first audience when she discovered information. She told them what she'd uncovered or discovered, and they would react to it, and then Skloot tells us how they reacted. My sense is that Skloot did not embark on her reporting project envisioning this complicated role for herself. I have been in the position of providing sources with information they did not yet know solely so I could then ask them what they thought of that information. Skloot does this on a grand scale. We don't know how she presents the information to them (neutrally? with a storyteller's ear for details? a reporter's love of zesty developments?), and, as much as ever, the reader has to trust Skloot as both informant and as recorder of the family's reactions. I find it intriguing that a story about trust and its violations requires so much trust in the author. Perhaps this is so salient to me as a reader

because Skloot herself finds it so as well. I'd like to believe she recognizes the gravity of her role.

Ann Miles

My concerns about informed consent, whether required or simply the decent thing to do, are further heightened because of some of the things the book tells us about the family, things that seem tangential at best to the story of the cells. It is easy for me to agree with the argument that the world needs to know the medical history of the cells, including the circumstances of their appropriation, their marketing, and their contributions to science. An open discussion of these practices needs to happen if we hope to learn from history and do better. As a reader I am also sympathetic to learning about the human consequences of what happened, in particular the fear, confusion, anxiety and anger that the Lacks family so justifiably feels. Understanding how the family was hurt and, frankly, exploited by waves of researchers and journalists is vital to recognizing the consequences of seemingly benign practices. But I am less certain about, and more skeptical of, the very personal details provided about Deborah Lacks and her brother Zakariyya. These details, mostly about their emotional responses to Skloot's investigation, are often provided without attribution to sources, and they are somewhat telling of their subjects' characters and the hardships they experienced in life. But those details went far beyond what I needed to know about them to understand their lives and how the loss of their mother and the promulgation of her cells made them feel. Because of the intimate details readers are privy to, I worry that Deborah's and Zakariyya's dignity were harmed in the process.

Consider again, for example, that first phone call between Deborah Lacks and Skloot. It is unclear if this phone call was tape recorded, but I assume it was not as Skloot reports that she took notes "frantically."[29] Was Deborah Lacks aware at the time that her words (which Skloot quotes directly) were being recorded in any way? Did, or could, Deborah Lacks really know that the audience of that cold-call would be literally everyone? In the end, our first impressions of Deborah Lacks are built from Skloot's report of this unscheduled and unexpected phone call and the description of her as "screaming," "confused," and "panicked."[30] Perhaps even more troubling is the conversation that occurs between Skloot and Deborah Lacks in the hotel after they obtain Henrietta Lacks's medical records. It is clear here that Deborah Lacks is concerned about publishing things that will

reflect badly on the family. In particular, she did not want Skloot to report that the medical records state that her older sister suffered from "idiocy." Skloot promises she won't use that word, but a "wild-eyed" Deborah Lacks doesn't believe her and throws Skloot against a wall.[31] Not only does Skloot—despite Deborah Lacks having asked her not to—tell us the records use the word "idiocy," even more troubling to me is that she does nothing to protect Deborah Lacks's dignity.

Their road trip and the events that transpired, set into motion by Skloot, clearly stressed Deborah Lacks to her psychological limits, putting her in a very delicate emotional and physical state. She was unable to sleep and was covered in stress-induced hives. Yet Skloot reports every word and action that transpired while Deborah Lacks was so clearly under considerable duress. While it may have been impossible for Skloot to keep Deborah Lacks from participating to the extent that she did, and while she may not have been able to control Deborah's responses to what the two of them uncovered, Skloot did have complete control over the story that she tells and what we learn about Deborah. What does a reader really need to know to understand a story, and how do we balance that with what is potentially harmful to the dignity of those who work with us? I couldn't help wondering at this juncture in the book if, at the expense of Deborah's dignity, Skloot was burnishing her journalistic reputation as someone who can literally take "hard knocks." By not seriously interrogating herself, asking hard questions about what the reader really needs to know and why, and without considering whose reputation is built and whose dignity is threatened in the process, she is as guilty as Dr. Gey was in assuming, unquestioningly, that she is doing the right thing.

Conclusion

We wonder how *Immortal Life* will be read a few decades from now. Just as the scientific researchers thought that what they were doing was right, so did Skloot, and in time her writing and reporting, too, may be reassessed. Research, whether academic or journalistic, that involves vulnerable human subjects carries with it considerable responsibility to the people who work with us. Having the ability or claiming the authority to write about the lives and emotions of others ought to be tempered by serious reflection on how power differentials should be negotiated both in our face-to-face interactions and in the production of our texts. While neither one of us would argue that writers and researchers should not

attempt to get right as much as there is a right to get, we also believe that it is necessary for writers and researchers to critically examine the processes in which they are engaged. Does getting it right necessarily mean telling it all? Ethics go beyond sticking to the principle of not paying an informant, and include much more nuanced considerations, such as those we have discussed above. The questions we have raised are not easily answered. Every writer makes choices about what information to collect, how to collect it, and what to report. As the preceding dialogue shows, we believe Skloot's path to creating her text was fraught with compromise and challenging decisions. Ultimately, only the reader can determine if Skloot has presented her audience with a meaning and a process that is acceptable whether wholly or in part. We are grateful for the questions this complex story raises because they enrich the context of future exploration of nonfiction texts.

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Endnotes

[1] Skloot, *Immortal Life*, 317.

[2] Hudson and Collins, *Biospecimen policy: Family matters.*

[3] Skloot, rebeccaskloot.com.

[4] Society of Professional Journalists, *SPJ Code of Ethics.*

[5] Pew Research Journalism Project, Principles of Journalism.

[6] Skloot, *Immortal Life*, 7.

[7] Ibid., 252.

[8] Radio Television Digital News Association, *RTNDA Code of Ethics.*

[9] Skloot, *Immortal Life*, 232–33.

[10] Ibid., 251.

[11] Skloot, HenriettaLacksFoundation.com.

[12] The notion of "partial" truth does not imply that ethnographic research is less able to get at "truth" than other methodologies, but rather argues that all truths are partial. Clifford, "Introduction."

[13] *Statement of Ethics.* American Anthropological Association.

[14] Skloot, *Immortal Life*, 53.

[15] Ibid., 51.

[16] Ibid., 49.

[17] Ibid., 198.

[18] Ibid., 52.

[19] Ibid., 54.

[20] Ibid., 55 and 67.

[21] Ibid., 277, 257, 298, and 299.

[22] Pitzer, *Rebecca Skloot on narrating history.*

[23] Skloot, *Immortal Life*, 233.

[24] SPJ, *Code of Ethics.*

[25] Skloot writes on pages xiii–xiv of *Immortal Life* that, "Members of the Lacks family often referred to Johns Hopkins as 'John Hopkin,' and I've kept their usage when they're speaking."

[26] Skloot, *Immortal Life*, 308–09.

[27] Ibid., 292.

[28] Ibid., 303–04.

[29] Ibid., 53.

[30] Ibid., 52, 53.

[31] Ibid., 283.