

## APPENDIX II

### CREATING *LISSA*: CONCEPTS, COLLABORATIONS, AND CRAFT

#### I. Key Concepts in the Story

*Q & A WITH SHERINE HAMDY, BY MARC PARENTEAU\**

**MP:** What gave you the idea to tell this story? What did you want your readers to get out of it?

**SH:** Coleman and I both did anthropological research on how social contexts shape medical decisions in very different sites—Coleman in the US, myself in Egypt—and on very different issues—Coleman on genetic risk for cancer and myself on kidney failure and organ transplantation. We were struck by the similarities and contradictions. During my research in Egypt, I encountered many people with end-stage kidney failure who refused to consider transplantation. This would sometimes frustrate their doctors. In one case I remember vividly, a middle-aged male nephrologist was particularly frustrated with his youngest patient: a woman named Maryam in her early twenties who refused to consider seeking a transplant. The doctor kept telling her, “You are young, and you have your life ahead of you! Don’t

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you want a life for yourself, a life free of this machine? A transplant could give you that life!” But the patient was despondent and kept repeating quietly that her fate was in God’s hands alone.

When I was reading through Coleman’s early work on women with BRCA gene mutations in the Netherlands, I was struck by a breast surgeon’s frustration with a young woman for the opposite reason. Anita lost her mother to breast cancer at a young age and sought out genetic testing as soon as she turned eighteen. When she found out that she had indeed inherited a BRCA1 mutation, she was adamant about getting a preventive double mastectomy. The doctor was agitated, as he recounted this story to Coleman, saying that “of course” he outright refused to do such a “drastic” and “irreversible” surgery on someone so young. He said that she was wrongly thinking that removing her breasts could somehow fix the grief she felt from her mother’s death.

We wanted to think through this seeming paradox. We thought, “What would it be like to bring together two characters with a strong bond of friendship, each of whom has to make a life-and-death medical decision that the other can’t understand?”

**MP:** That’s interesting. In the first case the doctor tells the patient that her young age is why she should undergo surgery, and in the second, the doctor tells his patient that she is too young to get the surgery. But these two scenarios are also two totally different cultural contexts...

**SH:** Yes, well, we knew that because of the very different sites, it would be tempting to turn to cultural explanations. But we did not accept at face value that in Muslim-majority settings, for example, people reference their fate and God’s will because they are somehow more “fatalistic” than others. This is a major trope about the Middle East in much Orientalist literature, in which Muslim “fatalism” supposedly contrasts with Euro-American innovation and invention. But this seemed overly simplistic: there were plenty of technology-embracing Muslims in Egypt and plenty of technology-averse (religious or irreligious) folks in Europe and the US.

We wanted to ask, “How do patients and doctors decide whether a medical intervention can really save a life or defy death?” In each of these real cases, the doctors’ and patients’ views are not aligned. And, in both cases, the patient [Maryam or Anita] is experiencing her illness and treatment as connected to the bodies and lives of other people. In the first instance, a kidney transplant relies on extracting a kidney from a healthy living donor. The physician telling

his patient to pursue kidney transplant sees this as an obvious choice because he is thinking on the scale of the patient's individual body.

The patient refuses, knowing all too well that such an intervention requires her enmeshment in, dependency on, and possible endangerment of *another person's body* (the body of the kidney donor). In the second example, on which we based Anna's story, it is an asymptomatic patient anticipating cancer in her own body, as she grieves her mother's death from that same cancer. The physician discouraging the young woman from pursuing a prophylactic mastectomy is horrified (as Layla was) at the thought of removing perfectly healthy body parts. But Anita's social embeddedness in relations of care—with her mother, aunt, maternal grandmother—and her enmeshment in the memories of their bodily suffering and death from breast cancer motivated her to seek medical intervention in the first place.

**MP:** So are you saying that this is why the doctors and patients aren't agreeing? Because the doctor is just looking at the patient as an individual while the patient is really bound up with the bodies of others?

**SH:** Yes, we really wanted to highlight what we call the "social embeddedness of the patient." Clinicians are trained to think about interventions with their patients at the scale of the individual patient's bodies, which of course makes sense from the medical perspective. But we see, for example, that often patients' motivations for seeking treatment are to become independent and to free their loved ones from the burdens of care or—in the case of high-cost treatment—to free their loved ones from the burden of the expense. In the case of many "previvors" who test positive for a cancer susceptibility gene, their own histories as caregivers, like Anna's history, make them feel that, in a sense, they have already lived with the disease. Anna's motivation to pursue surgery is partly based on the loss of her own mother to the same disease. For people who are trying to decide how to manage their risk medically, family obligations play an important role, whether it's getting surgery to protect your own children from having their mother die of cancer (Angelina Jolie wrote about this in her op-ed piece in the *New York Times*) or whether parents or siblings pressure a family member to get surgery because they are afraid of losing another loved one to cancer. There's also the broader issue about genetic testing to determine risk of disease—if one family member finds out he or she carries a mutation, the rest of the family is affected by that knowledge.

And in the case of Abu Hassan, the treatment option before him relies on his loved ones making an even greater sacrifice to keep him alive: an operation

with a high cost would deplete all their savings and possibly put them in debt, as well as putting them at risk of a major invasive surgery (in donation). The case of organ transplantation brings this discordance to the surface because this particular medical practice relies directly and materially on the bodies of other people. In other medical practices, dependency on others (as in the form of care-taking) is less direct yet is still essential to medical outcome. So by highlighting the problem of focusing on the "individual" and "autonomous" patient, we also wanted to expose what Annemarie Mol has noted about the problem of the tired dichotomy between the "West" and the "Rest."

**MP:** You mean the ways that "the West" is supposed to be about autonomous individuals and that, in "the Rest" of the world, it's all about traditions and tribes?

**SH:** Yes, Mol critiques the ways in which we tend to imagine that the autonomous individual is what defines "the West" in contrast to "Others" who are supposedly more embedded in their communities and more bound by tradition. But Mol asks, "Are people in the West indeed autonomous individuals?" She suggests that we contribute to the line of work opened by postcolonial studies not just by countering more tired stereotypes about non-Western "Others" but also by readjusting what it is we assume to be true about the West.

So we took up Mol's challenge, by following a character with an inherited gene mutation that predisposes her to cancer risk, alongside patients in Egypt with end-stage kidney failure. For both cases, the focus on the individual body as the site of intervention places patients in a double bind: to undergo treatment, they must privilege their own bodies over those of their relations, even while their relations are what enable or motivate that very treatment.

**MP:** I remember you also saying that the focus on the "individual" blinds us to social inequalities.

**SH:** Right. For example, near where I work, a billboard over the highway features an image of a white girl, maybe four years old, with large blue eyes and a seeming halo of blonde curls. The message reads, "Cancer doesn't care who it picks on." The billboard is meant to draw our attention to this one individual girl, who tells us that even children can get cancer; that it is no one's fault.

But we know from public health research that cancer *does* discriminate: people living in neighborhoods of lower socioeconomic status face higher morbidity and mortality rates in the US; those subject to mismanaged toxic waste face "cancer clusters," and discrepancies in susceptibility and outcome



are even more pronounced when we look at it globally, given the widening gap between rich and poor throughout the world. In the discourse on organ donation, the miracles of “saving lives” and “giving the gift of life” through organ donation similarly evoke the notion of individual, neutral, unmarked bodies who are equally susceptible to disease, whose organs, tissues, and blood are interchangeable.

This rhetoric comes up against the dark reality of a shadow market in body parts, in which body matter moves in patterns that Nancy Scheper-Hughes has starkly laid out: from the poor to the rich, from the brown- and black-skinned to the white, from women to men. It also hides the grim actuality that the world’s impoverished people who suffer from poor labor conditions, poor nutrition and unclean water, toxic exposure, and medical mismanagement are in fact more susceptible to organ failure in the first place.

Why does the rhetoric of the “individual, equally susceptible body” persist, despite decades of public health research that proves that bodies are *not* equally susceptible? People with less access to resources (such as secure employment, clean air and water, secure housing, education, racial privilege) are at much higher risk of illness. Medical practice is one of the key sites in which the myth of socially equal bodies is enacted through the promises and imperatives of individualized treatment.

**MP:** Another major theme and, in some ways, a point of conflict has to do with different ideas of what *causes* the disease.... Was it the pollution? Bad water? Bad genes? At one point, even Anna, who is focused on her genetic mutation, is freaked out by the toxicity of the chemicals she is using to develop film in the darkroom....

**SH:** Yes, we wanted to show that, with organ failure and cancer (both of which are illnesses with many complicated interrelated risk factors that can’t always be easily parsed or identified), patients have their own ideas of what might have predisposed them to disease. And these ideas about cause of illness would have an effect on their decisions about treatment. In my field research in Egypt, I saw many people with good reason to believe that toxic exposure had predisposed them to kidney failure. These were the patients who were wary to leave their beloved family members bereft of a kidney, to leave them in a sense amputated in the same environment that had made them sick. Maybe if they thought it was their own individual pathology or just bad genetic luck, rather than a shared environmental risk, they’d be more open to the idea of a brother donating a kidney to them.

Anna seems pretty sure that her genetics will predict whether she will get sick or not. The kind of cancer her mother died from is rare in that it can be traced to a specific genetic mutation—whereas the vast majority of cancers have really complicated etiologies. Anna’s decision makes sense to her because focusing on her own genetics is something she can better control. But it’s also not that simple. A BRCA mutation elevates her risk for getting cancer, but it doesn’t cause cancer. And Anna starts to recognize this in that moment in the darkroom, as she sees that her cancer risk is not just in her genes or in her family; it’s in her environment, even in the things she holds most dear, like photography. Ultimately, she decides that surgery is the best option in reducing her cancer risk.

So we see that different understandings of the disease (whether one thinks it’s caused by individual pathology or bad luck versus a shared environmental risk) shape how people make decisions about medical treatment, and how they view their illness in relation to the bodies of others.

**MP:** Back to the situation in Egypt. I get that you don’t want us to think of the characters as “fatalistic,” but why then do you think that they say things like, “The body belongs to God” or “My fate is in God’s hands”?

**SH:** For the young woman I first mentioned, Maryam, to evoke the idea that her fate is in God’s hands was a way, I think, for her to come to terms with the pain of knowing that her social relations had failed her—none had come forward with either the bodily or financial sacrifices necessary for a transplant. I often saw devout people going through difficult times evoking God as a way to bring themselves to accept the fact that they could not control or change what terrible thing was happening to them.

The physician expressed frustration at this, I think, because he did not want to accept that his medical skills were not enough to alter the patient’s grim prognosis. In other cases involving older patients, such as Abu Hassan, I often heard them say that their “bodies belonged to God” as a protective refusal of any of their children or spouses donating their organs to them. The surgery was seen as both a major bodily sacrifice and a financial cost, and one with an uncertain and complicated outcome.

**MP:** Even in Anna’s case—and she does not have the financial cost of her surgery to worry about—her decisions still aren’t easy.

**SH:** Yes, we wanted to show that the multiplication of patient choices in high-cost, high-technology medicine doesn’t always make treatment better. In the case of Anna, in the context of profit-oriented medical tests, she often

feels overwhelmed and burdened by her decisions. This is similar to what anthropologist Rayna Rapp demonstrated in her book *Testing Women, Testing the Fetus*, which explored amniocentesis in New York City. Geneticists and clinicians had assumed that screening pregnant women for potential genetic diseases would be a welcome intervention that could potentially reduce incidence of genetic disease in children and the burden of their care (via abortion of affected fetuses). Yet Rapp found that women, in many cases, felt alone and burdened by having to make these moral choices, by having to weigh the value of which form of life should be brought into this world. For many, particularly those with inconclusive results, this added significant stress and anxiety during their pregnancies. This “burden of choice” is also something that Marisa Marchetto captures really well in her comic *Cancer Vixen*.

To be clear, our point is not to criticize the use of high-technology, high-cost options in the space of the clinic but rather their indiscriminate and default use. We want to raise the question of how high-cost medicine can be used prudently to benefit patients’ experiences and outcomes. But we don’t have the ready answers! We want to open these questions up more to public discussion. Is the emphasis on individual “choice” the best way to go about handling questions like genetic risk? Is Layla right to think Anna’s worry about her genetic test is a problem of “too much medicine”? In what ways are medical ethical decisions similar across different settings?

**MP:** It seems like Abu Hassan and Layla are more realistic about a transplant not “fixing” his situation, whereas Anna is really hoping this surgery will erase cancer from her life. Does it? What was your thinking here?

**SH:** Well, in Egypt, which doesn’t have a well-functioning malpractice system for patient redress and where medical care can be especially uneven, there is certainly a lot of awareness about postsurgical complications, which is why people hope to avoid invasive procedures. In the case of Abu Hassan, we see that he never really believed the promise that a transplant would “fix” his kidney failure. Indeed, throughout the world many who receive transplants do not return to “normal” but rather transition to a post-transplant life that still must be medically regulated and monitored (albeit usually more easily than life on dialysis). After a transplant, patients should get at least six weeks of rest from physical or strenuous labor (which many people cannot afford), and they’ll need resources to pay for expensive medications such as immunosuppressants and for the medical management of opportunistic infections. It doesn’t make sense for a patient to liquidate *all* savings and assets for the hope

of a “fix” when the result is, in fact, more complicated: a life that will still require bodily and financial resources. Further, it is difficult, if not impossible, to anticipate how a kidney extraction in resource-poor clinical settings would affect the future life of a living donor, upon whom the operation depends.

As for Anna, well, we don’t get too much into this in *Lissa* because it would have distracted from the storyline. But Coleman found in her work with cancer “previvors” and survivors that too often this idea of “fixing”—with major surgery or treatment—can turn out to be a false metaphor, obscuring the chronicity of disease and the post-treatment complications patients can undergo. As Annemarie Mol has argued, the rubric of “patient choice” also implies that decisions are transactional, wherein the promise of biomedical intervention is the return to “normalcy.” Yet normalcy is forever a moving target in post-transplant life and pre- and post-cancer life.

**MP:** You’re also showing us the different and overlapping senses of time in disease treatment. In Anna’s case, she wants to get surgery for the *future* possibility of disease, but also as a form of redress for the *past* loss of her mom.

**SH:** Exactly. We wanted to ask how decisions about treatment would unfold if we had deeper discussions of the long-term consequences of medical intervention. What would a clinical encounter look like that privileged how patients’ lives are enmeshed in the lives of others, and how is their ability to imagine their futures caught up in their experiences of the past? Coleman and I were finding that, in organ transplantation and genetic testing, the biomedical ideal of patient autonomy just doesn’t align with the lived reality. The patient’s body, health, and choices are shaped by so many other things, such as intimate relationships and family obligations, as well as social context and political environment.

**MP:** Thanks, Sherine, you’ve definitely given us a lot to think about!

## II. Collaborations: On Comics, Coauthorship, and Ethnofiction

Q & A WITH COLEMAN NYE, BY MARC PARENTEAU

**MP:** Coleman, you both mention that you had really rich stories from your fieldwork that could easily have made for a compelling narrative. Can you tell us a bit about your decision to fictionalize your ethnographic research?



**CN:** Yes, the original ideas for this book were informed by our respective fieldwork on ethical dilemmas related to high-cost, highly invasive medical interventions in two very different settings. While we both had rich stories from our own research sites, we didn't have any research bridging the two contexts. So our major dilemma was how to make these two worlds—genetics in the us and transplants in Egypt—converge in a compelling, realistic, and accessible way. We decided to create a fictional narrative in which there were two main characters, each based on our research, whose worlds were deeply intertwined through proximity and friendship, and whose life trajectories reflected the broader medical tensions and affinities we wanted to explore.

So, while Layla and Anna are fictional characters (though they feel so real to us now!), they are not completely fabricated. Instead, they are based on what anthropologists call “composite characters.” Composite characters are modeled after real people, but rather than reflecting all of the traits of any one individual, they instead represent select traits, behaviors, or characteristics that are shared by a subset of individuals. So, for Anna, there are things about her character that might be generalizable to many (but certainly not all) other young cancer “previvors” in the us: she has lost several close family members to cancer, and she has to navigate a range of imperfect choices, financial barriers, and social pressures around how to manage her cancer risk. There were also specific choices we made as authors that were based less on data patterns and more on the specific story we wanted to tell. For instance, Anna's decision to forgo reconstruction after her preventive mastectomy is less common for people her age, but we had her story take this direction because of certain plot-based needs. If Anna had opted for reconstruction, it would have made it difficult for her to travel to Egypt so soon after surgery and to remain there for six months.

Beyond bridging our research sites, fiction really gave us the freedom to craft an absorbing, relatable, character-driven narrative—and the flexibility to adapt the narrative in ongoing conversation with our illustrators Caroline and Sarula, as well as with our interlocutors in Egypt who gave us feedback on what worked and what didn't.

**MP:** Anthropologists often use pseudonyms to protect the confidentiality of the people they are writing about. Were ethical issues, especially with the political turmoil in Egypt and the sensitivity around illness experiences, also part of your decision to fictionalize characters such as Layla?

**CN:** Well, yes and no. In the case of Anna and Layla, creating composite fictional characters certainly made sense in terms of protecting the identities

of people from past research who have trusted us with their personal medical stories. But, interestingly, in the context of the Egyptian Revolution, we have used the names and likenesses of several real people with their consent. You see, revolutionaries wanted to disrupt the brutal suppression of dissent under Mubarak. As part of this effort, they were announcing themselves publicly. The story we tell of the revolution comes in large part from the stories of those who took part in the revolution in Egypt who are named and discussed in their own memoirs, writings, blogs, Facebook posts, artwork, books, articles, and organizations. Their work and actions were in the public sphere, and this is now part of our living memory; we did not want to hide any of these characters or obscure the value of their work in our fiction, even as we recognize that counterrevolutionary forces today continue to punish and repress political actors of all stripes.

**MP:** Say more about this—actual people who are present as characters in *Lissa*.

**CN:** Part of this decision to include real people as characters was motivated by our awareness of problematic forms of Western “academic tourism” in the Middle East. We did not want to overshadow or wrongly claim the intellectual production emerging from the revolutionaries themselves and those most immediately affected by the political uprisings. We hoped to make it clear that the critical intellectual work on the revolution belongs to Egyptians, not to us, as outsiders. As part of this effort, we incorporated the work of a range of revolutionaries, intellectuals, and artists.

Two characters that Layla encounters during the Egyptian Revolution—Reem and Alia—are based on Reem Bashery and Alia Mossallam. These women's personal stories of the revolution were recorded by Egyptian feminist researchers from the Women and Memory Forum as part of an oral history project. Many lines of dialogue are taken directly from their narratives, and the work that Anna engages in around trying to locate missing people is based directly on Alia's experiences. For example, Alia Mossallam published an extremely powerful piece on her attempts to locate missing persons—and we used her firsthand account for the scene when Layla meets her in the morgue.

Readers might also recognize Dr. Dina Shokry as Layla's university professor and Dr. Amr Shebaita as her field hospital supervisor. We wanted to capture the actions of Tahrir Doctors [the NGO that Dr. Shebaita co-founded] and acknowledge our own research team's indebtedness in particular to Doctors Shokry and Shebaita, who have made tremendous contributions to health and justice efforts in Egypt, and who very generously gave us feedback on our original script.

We incorporated some remarkable work of graffiti artists, such as Ganzeer, who were already using illustrations in sophisticated and stunning ways to level trenchant political critiques. Through graffiti, we also make reference to Dr. Ahmed Harara—the dentist who lost his eye in the early occupation of Tahrir Square in January 2011. He was then shot by police snipers in his second eye the following November during the unrest in the Muhammad Mahmoud Street protests. And for fictional characters engaging in real events of the revolution, we wanted to highlight the tremendous work that Egyptians themselves were doing in the very acts of fighting off riot police, improvisationally healing the wounded, navigating censorship, and presenting competing counternarratives to state propaganda.

At each of these points of incorporation, collaboration, and citation, we hope to invite readers to challenge their assumptions about authorship and scholarly authority.

**MP:** Okay, so it's clear why fictionalizing made sense for you. But why comics? Why did you feel that illustration was needed to tell this story?

**CN:** Like other scholars working in the growing field of what Ian Williams has termed “graphic medicine,” we found that the combination of text and image in graphic memoirs such as *Hyperbole and a Half* and *Mom's Cancer* and *Cancer Vixen* powerfully conveys the visceral, temporal, and social dimensions of illness. There's also a levity to the genre that makes it easier to engage with difficult topics such as kidney failure, cancer, or political violence. Ultimately, we are convinced that this form of engaged scholarship opens up possibilities to convey the ethnographic encounter through an accessible, visually rich medium that allows readers to draw their own conclusions about how the material relates to their lives.

**MP:** It also seems that the illustrations did a great job at introducing readers to otherwise unfamiliar settings—the crowd scenes in Tahrir and the long shots of Cairo are especially powerful.

**CN:** Yes, definitely. We wanted to exploit the comic medium to bridge audiences in the Arab world with those in the US. We show that layering and juxtaposing multiple perspectives—from people who inhabit distinct world-views—can only benefit our abilities to examine difficult ethical decisions about life-and-death treatment and the stakes of partaking in political conflict.

One of the most generative aspects of the process has been realizing how much more we can convey through the combination of text and image. Far

from “dumbing down” content, comics allow us to convey complex, and often contradictory, anthropological ideas in a highly readable format. For example, the concept of political etiologies that took Sherine roughly 30 pages to describe in an academic article can be graphically illustrated in a two-page spread!

We show Abu Hassan, linked to a dialysis machine, its tubes snaking outward spatially and temporally, connecting the patient's sick body to the parasite-transmitting snails of the Nile, the overproduction of US midwestern wheat upon which the Egyptian population now depends for food, chemical fertilizers, pesticides, failing infrastructure, and the black market in counterfeit medical drugs and equipment. Following connections across scales and times is more fluid in graphic form, facilitating our work between two contrasting global contexts to expose a range of interconnected issues in health, politics, and justice.

**MP:** What was the actual process like: two authors cowriting the script and then working with illustrators? How did that work?

**CN:** It has certainly been a learning experience! Years ago, Sherine and I had talked about doing some collaboration based on our two research projects—we had even written an academic article for a workshop (that we never ended up submitting to publication) on some parallels we saw around the limits of the bioethical ideal of patient autonomy. I was still at Brown at the time, and Sherine had this idea to go down the hill to the Rhode Island School of Design (RISD) Illustration Department and propose a collaborative project with them. Luckily, we got funding for this from the Watson Institute at Brown. Rob Brinkerhoff of the RISD Illustration Department put us in touch with Paul Karasik, who teaches comics. Paul selected Sarula and Caroline as students who were ready for a big project like this. They were college seniors at the time, which is doubly impressive when you see the scale and sophistication of their work.

Sherine and I wrote the script together: we brainstormed the initial plot over the summer of 2015 and took turns fleshing it out in a Google doc. Paul gave us feedback on how to make it more visually accessible (the story has changed a lot since our first draft!). The following fall, we met Sarula and Caroline for the first time, and their first task was to sketch out the whole script. It was a lot of fun for us to see it all unfold, and it also made each team (the writers and the illustrators) ask hard questions about what each scene was doing, why it was necessary for the plot, etc. It has been a remarkable learning experience, as we have had to translate our anthropological insights



and imaginaries for the illustrators, and they have had to teach us about visual language and the technical dimensions of building comics.

And then there was the added issue of how to depict Egypt. Only Sherine had been there before, and we were all relying on her for the visual scenery. Thankfully, Sherine got funding from the Luce Foundation to take the whole team to Cairo. It was an incredible trip, and the story took on new depth and direction as we really began to place the characters in Cairo.

We were lucky to have ethnographic filmmaker Francesco Dragone and medical anthropologist Alice Larotonda to film this whole process in a “behind-the-scenes” documentary. Our aim was to make our methods and process available to other scholars and artists who wish to embark on similar illustrated forms of scholarship and to reflect on the ways in which new forms of visualization allow for communicating academic research—ethnographic, scientific, medical, humanistic—to broader and more diverse audiences.

**MP:** And how did it work to have two different illustrators?

**CN:** As for the two artists, each decided to take on a character. Initially, Sarula chose Layla and Caroline chose Anna, but then they switched! Sarula works digitally and Caroline draws traditionally with pen and paper, and they worked really well together to balance their styles. This worked in terms of the plot, because the initial idea was for two characters with different perspectives to slowly come to understand one another. So we see the world through Anna’s eyes in Sarula’s style and then the world through Layla’s eyes in Caroline’s style, and then . . . when they come to understand one another toward the end, the two different styles merge.

### III. Crafting Comics: Time, Space, Text

*Q & A WITH MARC PARENTEAU, BY EDITOR ANNE BRACKENBURY\**

**AB:** Marc, you’ve had a very interesting role in helping to pull this all together, especially toward the end. Since this is the first book in our *ethnoGRAPHIC* series, we wanted to make the process clear as other ethnographer-illustrator teams embark on their projects.

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Could you tell us what your role was in helping the authors and illustrators along?

**MP:** Sure. First I should say that it’s been a pleasure working with the *Lissa* team, and I have learned a lot in the process, which I am very grateful for. That said, I think it’s fair to say that most academics aren’t overly familiar with the contours of comics as a medium and how they affect the writing of a script. On *Lissa*, I found that the most common difficulties were either rhythm/pacing issues or descriptive/dialogue issues.

The way writing comics—for print anyway—is most affected by rhythm is that, at a minimum, you really have to know if what you are describing occurs on a left-hand or right-hand page, the reason being that, when you open a comic, you can’t help but scan the entire two-page spread. So, if Grandma dies on the right-hand page in a comic, the reader knows this before they ever start reading anything on the left. Having reveals of that sort in the wrong place can ruin the “pull” that you want the reader to have throughout the work.

**AB:** I guess that’s what people mean when they refer to the “dual nature” of comics—that you can read it sequentially panel by panel, but you can also get the big picture on a page, or two-page spread, in a way you don’t get when you are reading a text-only book. So what does that mean in practice?

**MP:** Since you have multiple visual elements pushing and pulling with—or against—each other, you have to consider things both in terms of the static composition of the spread and in terms of the flow of the content and composition of image and text within individual panels. There are a million ways to do this in comics, but I think essentially you’re aiming for a kind of “readable” circulation of meaning among those multiple elements. It’s both challenging and exciting from a creator’s point of view, and really unique in terms of what it can provoke in the mind of a comics reader.

**AB:** OK, that makes sense, but then how do you decide on how many panels are going to go on each individual page?

**MP:** In terms of an individual page, it depends on a lot things: whether you want things to move quickly or whether you want to draw something out, whether you need the visual emphasis of a full page, etc. But in order to unify a project visually, I think it helps to decide in advance how many panels will be your “basic unit.” I liken this to choosing the meter of a piece of music. For *Lissa*, the meter is 8/8. That is, generally speaking, there are two columns and four rows of panels per page. It doesn’t mean that you can’t deviate from that number; it just means that the deviations from that panel pattern happen

in reference to an eight-panel grid. It's kind of like how, in a piece of music that is in 4/4 time, you can still play triplets, have syncopation, counterpoint, etc. So the writer always has to consider whether what's being described will fit in a two- or eight- or however-many-panel sequence.

**AB:** So who decides this rhythm or meter—the writer or the illustrator?

**MP:** In terms of the work overall, I would say that the writer needs to figure it out before handing it to an illustrator. It's hugely helpful if the writer develops a script that discretely reflects what is happening on a page-by-page and panel-by-panel basis. So the script looks much more like a screenplay. There are plenty of ways to do this, and whatever works for both the writers and the artists involved is clearly fine. But I tend to format things like this:

Page 22 L

22.1 [i.e., Page 22, Panel 1] Mom is running towards house. Mom: Don't go in there!

22.2 Hansel turns head quickly towards Mom's voice. Hansel: Huh?

22.3 Mom's face close-up. Mom: My pies are still in the oven!

22.4 Hansel's face, downcast. Hansel: You mean me and Gretel have to wait another 20 minutes to cook this old lady who tried to eat us?

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23.1 etc. . . .

I prefer this kind of breakdown when I illustrate for other writers because I can immediately see what action and what dialogue goes with which panel. That way, if I have a question about or a need to change something, I can clearly cite panel and page.

**AB:** That seems straightforward, but I can imagine all sorts of scenarios where the writer either gives too much information or not enough for the artist to work with.

**MP:** Definitely. Most problems come out of the fact that words are often more spatially dense than images are. So, for example, it doesn't generally work to have an elaborate sequence of events occurring in a single panel.

*"Larry gets up, brushes his teeth, and stares in the mirror thinking about the cruise ship."*

This is one sentence, but it's probably at least three panels if you want to actually show those things. And while we're talking about Larry staring in the mirror, a description such as this—

*"Larry thinks about the cruise ship, he feels the weight of all the lost souls on his father's ship, which went down in rough seas off the coast of New Jersey while steaming towards a summer in the fjords of Norway."*

—is probably not a single panel either, and definitely not a visual direction unless the writer says that we *see* these thoughts in the form of flashbacks or thought bubbles or some other such device.

This means that unless a character or narrator says it, all descriptions of emotional or interior states must be stated in the script in explicitly visual terms or else they are essentially superfluous.

**AB:** What about dialogue? Are there rules for how much dialogue should be included in any given panel, and do you sometimes have to edit the content of a word balloon to fit it inside a panel?

**MP:** Copy-fitting of dialogue is a constant concern. Having a single balloon with a 150-word statement in it will slow the readers down to such a degree that you can lose them. My rule of thumb is no more than 30–35 words per balloon, maximum. Fewer is generally better.

**AB:** So you have to think visually when you are writing the dialogue so you can imagine what the visuals say and what the text says?

**MP:** Yes, but in my view, dialogue and visuals in comics should pass off the meaning(s) of a work the way that runners pass off a baton in a race. The main difference between my analogy and a real race, though, is that comics should cheat. What I mean is, dialogue should *push the visuals forward* when it hands the baton and the same thing vice versa. So, if you have a panel depicting an angry man, and in that panel the angry man says, "I am an angry man!" Then you could say that rather than passing the baton and giving each teammate a boost, the two runners are battling over the baton, and the reader doesn't know whom to root for and/or thinks the team is very undisciplined. I think these problems happen mostly because, while a writer is in the depths of writing, it can be tough to keep track of where that hand-off is taking place at any given point. I see my role in team *Lissa* as being the person who keeps an eye on all the above. That way, both the writers and artists have maximum latitude to explore the landscape of the medium. I suppose you could say that, if they get stuck or lost, it's my job to go out and find them and get them back on track.

**AB:** Speaking of keeping things on track, there are around 1,500 individual panels in *Lissa*. How did the artists keep their drawings consistent



throughout such a large work? Was there a similar sort of copyediting that took place visually as there was for the text in the comic?

**MP:** Sarula and Caroline are both very strong artists in their own right, and they did a tremendous job tackling a project like this. They somehow managed to share pages and blend styles in a single, unified way that is extremely difficult to do. As many times as I've been through the book at this point, I am still impressed at what they achieved. But you're right, there are just an awful lot of images to draw in a project like this, and it can be quite difficult after hours of working on a page to remember that, on the previous page, a given character was actually wearing a bracelet or *didn't* have her hair tied up or what have you. So throughout the drawing process, I often sent the artists back annotated drawings pointing out, "This character should be looking left" or the like, which must have been supremely annoying for Sarula and Caroline to hear after hours of work. But they were both very gracious and patient with my pestering. So yes, I did keep a close eye on continuity, both in terms of examples like I just mentioned and in terms of consistent facial expression, body language, or other sorts of nitpicky little things that can slide when you're several hours into a page. If you find any fault in the book on that score, by all means you can blame me! Otherwise, the other visual contribution I made was getting to add in sound effects, which I really enjoyed.

## APPENDIX III

### TEACHING GUIDE

#### I. Discussion Questions

1. In what way does Anna's family cancer history shape her relationship to her body and her future?
2. Why does Layla think it's crazy for Anna to "treat a disease that she does not have"?
3. Why can't Anna understand the reluctance of Layla's family to consider a transplant for Abu Hassan?
4. In what ways do we see bodies and body parts being commodified (treated as commodities to buy and sell) in both the American and Egyptian medical systems?
5. Layla imagines that there wouldn't be ethical dilemmas in the United States, given how much more resource-rich the medical settings are. Based on Anna's experiences, in what ways do more resources resolve certain medical problems and *exacerbate* others?
6. The biomedical approach to illness often conceives of the patient as an autonomous individual whose health, body, and decisions are that patient's

El-Seht (Twins Cartoon), and Professor Agnes Michalczyk and her students Alaa Darwish and Asmaa Moustafa. Dr. Dina Shokry from Kasr el Aini Forensic Medicine and her students, as well as Dr. Amr Shebaita from Tahrir Doctors, contributed much to the medical dimensions of our story and make appearances as themselves in the novel. Our respect and thanks go also to the Egyptian artists whose street art and graffiti we cite in the pages of this book. We are most deeply grateful to Ganzeer, who so generously designed the stunning graffiti composition on the final page of the novel. And we are indebted to Mohamed and Zainab for opening their home to us during our visit. Back at Brown, the Pembroke Center and Ed Steinfeld, John Mazza, and Alex La Ferriere from the Watson Institute continued to support us; Soha Bayoumi, Ahmed Ragab, and Mariz Kelada provided helpful feedback and input on the script; and Myra El Mir graciously helped with the art. We also thank Ian Straughn for helping us acquire key Egyptian comics and texts coming out of the revolution; Harriette Hemmasi from the Brown Digital Humanities Initiative; Khaled Al-Saai for hand-lettering the gorgeous calligraphy on page 219; and James Young, Krissy Pelley, and Emma Funk for their design ideas. Our final thanks is to Marc Parenteau, for his sustaining friendship and camaraderie, and for helping in the final essential stages with visual translation, pacing, lettering, and coaching. We all feel lucky to have been part of a remarkable team and are above all grateful to one another.

## Note on Transliteration

As any scholar working in Egypt knows, using a consistent system for transliteration from Arabic sources is often a challenge. When making decisions about how to render proper names, we chose to use people's own spellings, in cases in which they have published or presented themselves publicly in English, rather than to follow standard academic transliteration. In the script and dialogue of the graphic ethnography itself, we use "ee" for the long vowel—*ē* as in "eagle"—even though guidelines from the *International Journal of Middle East Studies* suggest writing this vowel as *ī*. We also decided to go with popular spellings of common phrases. So the phrase "God willing," for example, is rendered "inshallah"—to reflect the sound of common speech.

## FOREWORD

### LISSA AND THE TRANSDUCTION OF ETHNOGRAPHY

GEORGE E. MARCUS\*  
UNIVERSITY OF CALIFORNIA, IRVINE

"Transduction: the action or process of converting something, and especially energy or a message, into another form."

*Webster's Third New International Dictionary*

The graphic novel *Lissa* forges a new path, instructing anthropologists and academics more broadly in remaking their work into new forms. Selecting the graphic novel form was inspired in itself, though many scholarly producers of long-form accounts—in sociology, philosophy, journalism, history, and biography especially—have experimented recently with the graphic novel. A shift to comics provides a move from ethnography to a popular narrative form that crosscuts high-low aesthetics and is present as a popular, affordable, and intellectually favored form in so many countries and regions, at a time when anthropologists are particularly eager for public and diverse receptions as a response to the continuous worldings of its once-contained field sites.

The question (and adventure) for Hamdy and Nye is how to achieve this shift. The parallel story of how they did—told in multiple media including comics, academic prose, a website, and a documentary film alongside the

\* George Marcus is a Professor of Anthropology at UC Irvine who is widely celebrated for his writings on ethnographic methods and writing.



text—not only enhances the enjoyment of *Lissa* but is a methodological exemplar for other anthropologists whatever their experience with ethnography.

Ethnographies were originally established through the identity of the lone fieldworker amid made and found relationships among subjects—or, at least, this was an operating fiction of ethnographic writing. Here Hamdy and Nye transduce original “field” or spaces of fieldwork into a different genre or aesthetic of form altogether. This shift into a form in another medium requires, yes, perhaps personally learning other arts, but it most likely thrives in collaborations, in the cooperative reorganization of the field and of the standard habits of representation from which ethnography originally emerged. And such collaborations require skills of diplomacy, entrepreneurship, friendship, and a tolerance for the capacity of changing events along the way to transform the scales and qualities of what one as a scholar and as an author had established before.

Hamdy and Nye establish an intellectual affinity, and a desire to experiment, based on the comparative similarities they perceive in their differently located ethnographic research projects within medical anthropology. Their move to express their excitement by co-producing a different form and by exploring it beyond professional publications places them in new methodological terrain altogether. This is the terrain of alternative forms for the expression and development of ethnographic knowledge beyond long-standing, marginal experiments with alternative aesthetics. Collaboration between them first involves scripting a storyline that is both fictional and true to ethnography. Collaboration further becomes much more complex and challenging, requiring patience, organizational skills, and entrepreneurial talent. Such collaboration makes ethnography plural far beyond the earlier critiques of submerged or repressed polyphonic representation in classic ethnographic writing up to the present.

Crucially, there is the finding, recruiting, and incorporating of artistic talent. Fortuitously, Rhode Island School of Design (RISD) is close to Brown University, Hamdy's base. RISD's culture of comic artists and producers brings norms of collaborative openness (figuring out problems in studios) that the project needs. Grants are gotten (!), and the team goes to Cairo, the artists seeing places that the ethnographer (Hamdy mainly, but Nye as well in the comparative imaginary played out in the narrative) has seen with “new eyes,” thus giving the ethnographer a new vision as well; the script becomes the new ethnographic reality. In the meantime, history itself has intervened, and

events (in Tahrir Square and after) present a different Cairo to all (as vision itself becomes a key trope of Hamdy's concern with the blinding of revolutionaries as a distinctive form of repressive violence). From an anthropological perspective, this is a second act to earlier fieldwork with new dimensions, representational challenges, and events unfolding, but with the historical narrative of change not yet legible. The script and the visual narrative created for it—changing in word, sight, and narrative as events unfold—provide the foundation for new ethnography on site, in plural dimensions.

Prominent among the diverse new constituencies for this project in the making are Egyptian comic and graffiti artists sharing a transnational, embedded readership for the form that ethnographers Hamdy and Nye and their team are now developing. The world of anticipated anthropological reception is joined by a shift in form with other constituencies, notably local artists who trade in bridging vernacular and cosmopolitan tastes rooted in “local knowledge” (cf. Clifford Geertz) that become “nervous systems” (cf. Michael Taussig). The graphic novel, to have any impact at all, must have several constituencies across cultures. It imposes a higher standard for ethnography that is transduced into this popular (and proudly pulp) form.

Thus, for the many anthropologists today who have argued broadly for a public anthropology as the central purpose of their discipline, the collaborative entanglements in the production of *Lissa* offer the exemplar of a way forward. What is ethnographic becomes diffused in the collaborative making of another form, which has diverse readerships and a visceral temporality fashioned within the recent past and the near future. Ethnography within limits has refined many of these qualities in its own genre form in recent years, and in fact the graphic novel in its succession to first projects might be thought of as calling for the integration of forms of ethnographic production long considered marginal or perhaps eccentric, but now eliciting an opening of anthropological ideas to new and crossover receptions.

Beginning within the circle of common practices of anthropological scholarship and mutual excitement through sharing comparative ethnographic knowledge, *Lissa*'s creators establish a path to broader public receptions by transducing recognized ethnographic results to a form, in a sense, designed for circulating recursively in the worldly conditions that have defined the same original ethnographic projects. The craft of the graphic novel form is thus not supplementary or parallel to the original acts and genre writing of ethnography but a mature move into a second project in which the



ethnographic becomes diffused in the making of other forms—and these other forms have diverse readerships and a temporality expressing both depth and emergence. Ethnography has many of these qualities, and in fact the graphic novel in its succession is a kinetic version of ethnography on the page.

The graphic novel, in succession, is yet another plateau in career scholarship. Where the latter then leads will truly depend on the broader and more diverse receptions that the graphic novel form offers, as well as on the stakes and the depth of the relationships in the collaborations (and the “second” fieldwork that they involve) for continued question-asking and problem-setting. Anthropological scholarship becomes driven by broader frames of reception than monographs and scholarly articles could hope for. Through this transduction, then, ethnography becomes a “public” good. This public anthropology is not a claim on the commitment of traditional ethnographic projects but a form for producing this anthropology today.

*Lissa* (meaning “not yet,” “still,” “there is time”) is the unfolded essence of the human predicaments that the story tells, and it is also, in parallel, the essence of the collaborative process that has produced the novel. It is an exemplar of what’s next, and doable, with clear lines to ethnography as a fulfillment of its narrative desire for diverse receptions (the latter day “can the subaltern speak?”—beyond the suspicion that she can’t, at least in ethnographic writing). What comes after can be answered only by how a collaborative travels. This is more making, doing, than hoping for, in the longing for a public anthropology that tests its ideas, arguments, and findings as vernacular storytelling across cultures. The hope for this transduction of ethnography as public anthropology is expressed by the sentiment of *Lissa* itself—both within its story and among those who have made it: “still time, yet.”

## PART I

# CAIRO





## **AFTERWORD**

### **READING *LISSA***

PAUL KARASIK\*

A friend told me about his recent ride in the Tokyo subway. He sat across from a woman reading one of the ubiquitous monthly manga magazines, not an uncommon sight. Though he tried not to pay attention to her absorbed reading of the digest-sized, square-bound comic book, the sound of her rapidly flipping through the pages was riveting.

They got off at the same stop just as she finished the book.

My friend, a cartoonist, was stunned and shaken. It could take him a week to complete a single page of comics. In the time it took this reader to consume a couple of hundred pages of comics, my friend might have penciled one panel.

There is something so beguiling about the combination of words and pictures in sequence that, once you start, it's hard to stop turning the pages.

Generally, cartoonists structure a page of comics to be easily tracked. If the reader is confused about the order of who is speaking in a panel, for instance, and the reading is detoured, the cartoonist has not done a good job.

But tracking is only one of the tasks. The cartoonist may purposefully use the language of comics to control what the reader knows and, equally important, what the reader *feels* about the information in ways the reader may never notice.

That subway reader sprinted, charging on to find out what was going to happen next, but the cartoonist was no doubt subliminally creating layers of meaning that enhanced the reading, even at that rate of absorption.

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\* Paul Karasik is a cartoonist and comics instructor at RISD. He selected the artists Caroline Brewer and Sarula Bao for *Lissa* and supervised their initial artwork.

*Lissa* is a complex story spanning two cultures, two families, several medical emergencies, and a sociopolitical revolution, but it never feels confusing. You may not be able to (or want to) read it in a single subway ride, as one is intended to read manga, but it flows smoothly.

This is no less an accomplishment given the fact that it was written by two authors—Sherine Hamdy and Coleman Nye—who have expertise in different fields of research, and that it was drawn by two artists—Sarula Bao and Caroline Brewer—who have two distinct drawing styles. All together, they have figured out a unique and clever way of taking ownership of parts of the story while weaving them into a cohesive whole.

This team is more than merely interested in giving you a clear, smooth ride. The authors and illustrators take advantage of their specific knowledge of how comics work to feed the reader more than just the surface story.

Perhaps if I highlight in this introduction a few examples of their control of the medium, the reader can begin to see how intentional cartooning creates layers of meaning and implicit understandings.

\* \* \*

Let's take a look at the depiction of Anna's father. Anna, one of the two main protagonists in *Lissa*, is close to her mother, but her father remains distant. When she needs him, he is not fully there. He is not antagonistic toward his daughter, just unconnected and preoccupied with his work. The artists reinforce this distance by not showing his face, having it obscured, cut off by the panel framing, or, in a scene located at the beach, just barely rendered.



It is at the turning point in the father-daughter relationship that his face is suddenly revealed. At that moment, what is also revealed is that it has taken Anna's change of heart to effect the manifestation of her father (and his face) in her life. He has not been the only one keeping them apart; it has been in Anna's power all along to bring him into her heart. The authors make this clear in the dialogue in the panel just before his face is revealed. And when his unexpected face suddenly appears, words collide with pictures and comics magic occurs.

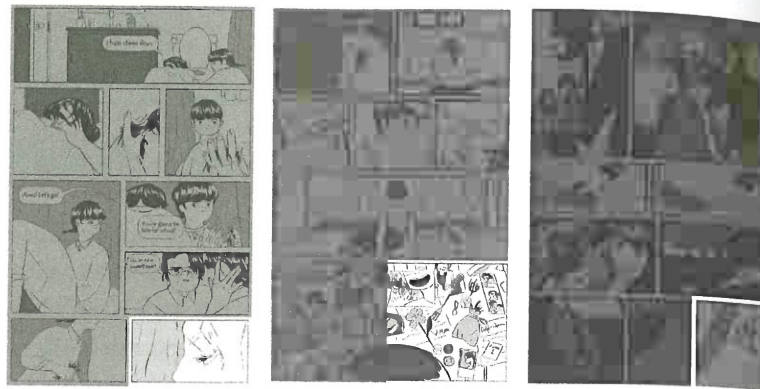
Words and pictures conspiring together to create meaning and understanding in this fashion can only happen in comics.

\* \* \*

Early on, the reader learns that Anna's mother has cancer. A brief scene of the daughter comforting her mother in the bathroom ends with the mother losing clumps of hair, as a consequence of her chemotherapy treatment. Anna pockets those clumps, and the reader forgets that she has held onto them until 9 pages later in the book, when the reader sees Anna putting together her "memory box" and is reminded of the hair in a panel that is located in the same spot on the page as the earlier one: the lower right corner. Another 13 pages after that, the pouch of hair emerges again in Anna's pocket, this time in a panel sequence composed in the same manner as the original.

This is done without any redundant text to underline the obvious because, in comics, there is usually no need to both tell and show. The reader instantly makes the connection to that earlier moment, and a very specific emotional bridge is deftly constructed visually. Again, this is a certain type of visual resonance one can feel only from comics.





\* \* \*

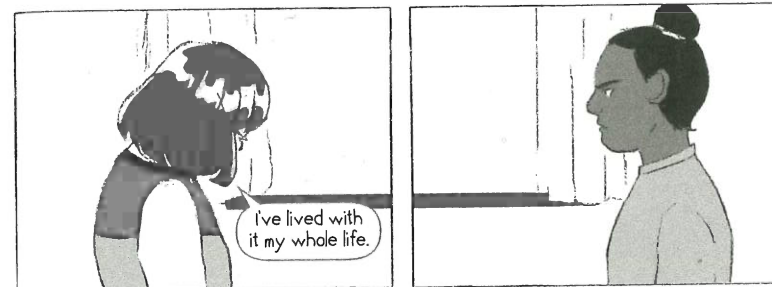
As the end point of a comics page, the bottom right corner is a key location. It can be used to conclude a scene or to pose a question or as a cliffhanger to urge the reader to flip to the next page. Here are a few lower right corner panels lifted out of context. Without knowing what comes before or after, notice how compelling they are. Throughout the book, the creators use this vital location—the lower right corner panel—in intriguing and unexpected ways.



\* \* \*

A tier in a comics page is a horizontal row of information that can be used strategically to relate moments in a tight, brief sequence. Throughout *Lissa*,

the artists employ the tier to explore the relationship between the two protagonists, Anna and Layla. More than once, the artists use the panel gutters to reinforce the gulf between them.



Their friendship ebbs and flows. After a dangerous event separates them, they rush to each other's embrace to reunite in a single panel.

But then personal secrets and misunderstandings pull them apart again on the very next page, with a literal space separating them.



\* \* \*

Moving from an analysis of single panels, through tiers, let's look at the design of an entire page that shows Anna on the cusp of making a life-changing decision.



In this tour de force of whole-page design, the creators show Anna weighing her options on an airplane surrounded by strangers. An establishing shot at the top of the page shows her smack-dab in the center of the panel, the seats of strangers drawn in curved exaggerated perspective stretching away from her. This composition cues the reader as to her self-absorbed mental state.



It is not a huge leap, then, for the reader to go bouncing from side to side as strangers are replaced by Anna's visions of friends and family giving her advice. It helps that the word balloons are abnormally jagged, tipping the reader off that these are voices of a different sort.

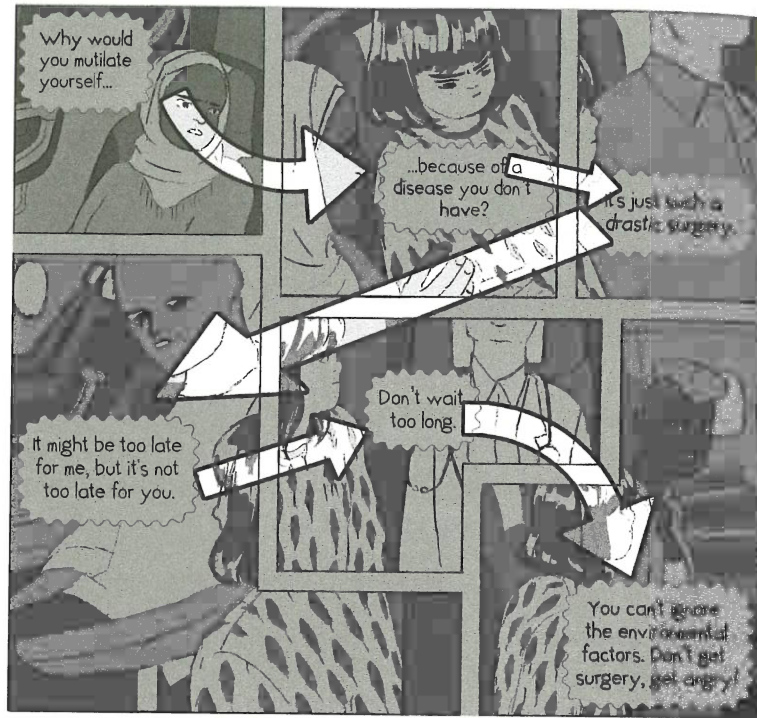
Note how the artists use Anna's shirt to identify her and to anchor the page. Her uniquely patterned top makes Anna instantly recognizable and allows for swift visual tracking as she turns her head back and forth, hearing the voices of imaginary advisors in her head.

The irregular shape and size of the panels help to simulate the herky-jerky rhythm of Anna's head swinging from side to side, yet the page is so thoughtfully composed that we never lose track of the correct sequence of events. Imagine the same page with panels of equal shape and

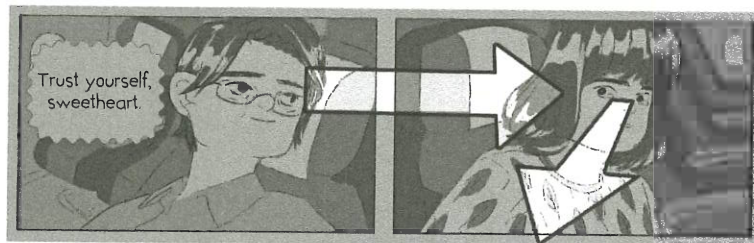




size, which would create a monotonous and calm rhythm, out of step with Anna's turbulent mindset.



The specter of her mother appears in the penultimate panel with a word of motherly advice. Then, in the final panel, Anna turns toward her phantom mother. Or is it the reader to whom she turns? Because of Anna's direct gaze, we *become* her mother, and there is a look of concern on Anna's mute face, which cannot help but move the reader who has been deftly jockeyed into the place of the mother.



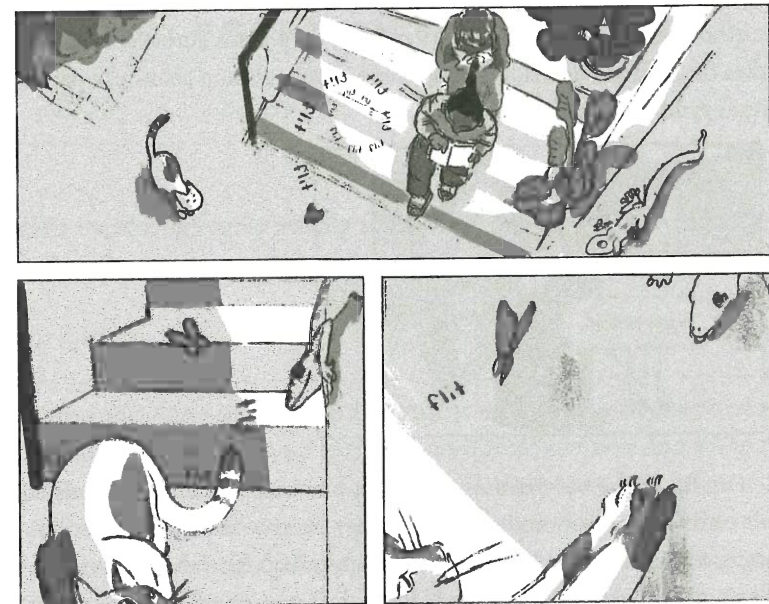
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A minor but significant detail in that last image is the row of empty seats behind Anna. Over the course of the page, the full plane with flesh and blood passengers has emptied out.

This sneaky detail, overshadowed by Anna's expression, seems subliminally to underline Anna's feeling of isolation as she struggles with her internal conflicts.

\* \* \*

*Lissa* spans years. As links, visually connecting the friendship of the protagonists, cats prowl throughout this book. They first appear on page 20 when Anna and Layla are young:



When the girls separate, Layla has a cat to comfort her:



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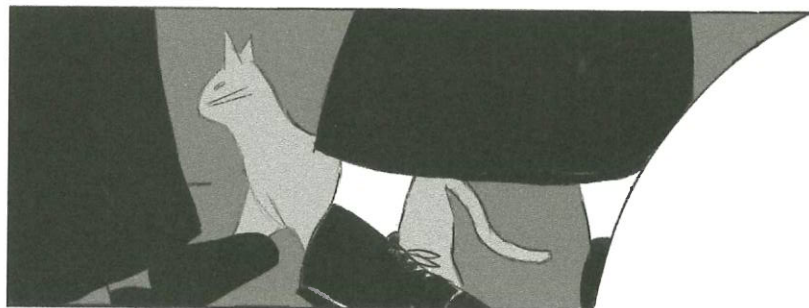
When they reunite several years later, a cat is there alongside Anna and Layla.



And when Anna hears Layla's call for help from across the ocean and makes the difficult decision to overcome bitterness and reunite, a pair of cat statues symbolizes their deep bond.



Finally, at the very end of the book, just before the two friends lay all their cards on the table and realize together the true meaning of sacrifice and justice, when they realize that their actions today affect themselves and others tomorrow, when they realize that the dark past could be a stepping stone toward an optimistic future, a cat links their history and leads the way... showing them that there is still time.



## APPENDIX I

### TIMELINE OF THE 2011 EGYPTIAN REVOLUTION

*A select timeline of events leading up to the revolution or pre-revolution, as depicted in Lissa:*

*JUNE 6, 2010*

*Layla and Anna both follow the events around Khaled Said's death. Layla becomes involved with the April 6 Movement, and Anna follows the Facebook posts and international coverage.*

- Twenty-eight-year-old Egyptian Khaled Said is brutally beaten and tortured by two police officers in Alexandria, after reportedly posting a video to the Internet showing several officers sharing the spoils of a drug bust.
- Images of Said's brutalized face circulate widely, and he becomes a symbol of the corruption and violence of Mubarak's security forces.
- Five days after Said's death, Wael Ghonim, Google's head of marketing for the Middle East and North Africa, anonymously creates the Arabic-language Facebook page "We Are All Khaled Said" to protest rampant police brutality, torture, and corruption. In January 2011, the page becomes a hotbed of planning and activity for the members of the April 6 Movement and others mobilizing for the Day of Anger on January 25.