Images of Things Human: Toward an Ethic of the Making and Interpretation of Ethnographies, Ethnographic Film, and Documentaries

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Introduction

In a chapter for the volume *Social Suffering* entitled "The Appeal of Experience; The Dismay of Images: Cultural Appropriations of Suffering in Our Times," Arthur and Joan Kleinman call for an intervention in the global appropriation of images of suffering, such that "global representations of local context" replace the mere "globalization of local images" (1997: 18). In this article, we expand upon the Kleinmans' previous writing to consider particular representations of suffering-those predominant in the field of global health—and their frequent failure to affect meaningful, long-term change for their subjects, despite the emergence of global health issues as the primary access point by which many in the West conceive of suffering abroad. (Global health has in fact become the major moral movement of our time, yet its uses and abuses of representation have hardly attracted attention.) Central to this genre, and perhaps also to its shortcomings, are techniques of crisis-making that place every disorder on a single plane of contestation from which experience-near judgments are rendered inapplicable. Forced through well-established templates of representation, the experience of paradox, so central to modernity itself, is squeezed out of the stories of sufferers. Something of the human is lost in the processsomething, we argue, that is vital to the ethics of global representation.

Anyone involved in global health can tell you the importance of "crisis." With limited resources, the twin specters of donor reluctance and donor fatigue greatly impact decisions made regarding the representation of suffering to a global audience. Consider the popular refrain employed in global mental health: by the year 2020, unipolar major depression will be the second biggest contributor to the Global Disease

Burden. This statistical representation was facilitated by the adoption of DALYs (disability-adjusted life years) to quantify human suffering in the late 1990s (WHO Information Office 1999, Ustun 1999). By complementing mortality as the metric by which the seriousness of human suffering was calculated, instead focusing on the number of years an individual spends disabled by any given disease, the Global Burden of Disease highlighted mental illness as a global health crisis-in-the-making.¹ In response, the World Health Organization promptly launched a program to "Stop Exclusion, Dare to Care" (World Health Organization 2001) which turned mental illness, previously given little attention in global health agendas, into a priority (although for a frustratingly short period of time). Situated near the apex of a hierarchical conception of suffering by which resources are allocated and interventions made, mental illness was soon displaced by the AIDS epidemic and its associated infections and pushed far down this list of priorities. As scholars of medical anthropology and global mental health, we do not wish to imply that such orientations are unnecessary or unmerited. Rather, we wish to highlight the power of representations of sufferingin this case, as a newly adopted statistical standard-to socialize suffering, and to comment on the added instability that the social can bring to experiences of suffering, as doubtless many of the mentally ill have witnessed with the ebb and flow of global mental health agendas.

"Crisis" is not always represented by numbers, however. Images of suffering are vital to generate public support and external funding for global health programs. As one of us, Arthur Kleinman, explained in an interview with *Atrium*, after receiving criticism for including photos of mentally ill individuals in an article he had co-authored with Vikram Patel:

Pictures are crucial in advocacy and mobilization. If we are to tell the global human stories of injustices, discrimination, and abuse among the seriously mentally ill, then we must see the real people in real conditions. The unwillingness to do so, often defended in the name of ethical protection of human subjects, is tantamount to silencing those with the greatest suffering and need for help (Watson 2009, 2-3).

Indeed, the lack of representation of "real people" living with mental illness in "real conditions" is considered one of the main reasons that the global mental health agenda has not achieved the same sustained support as have cardiovascular and other top global disease burdens. Stigma remains a major barrier.²

Even when images of suffering are prolific and a disease does attain high visibility, new tactics may assert the possibility of control. Take one slogan of the American Breast Cancer Association: "Imagine a world without breast cancer." For any person knowledgeable about this condition, it is pure utopian fantasy to imagine such a world. This bit of hyping asks us to imagine a reality that is impossible to realize, so distant from the on-the-ground conditions as to be entirely absurd. Yet it

succeeds where other approaches foregrounding statistics, testimonials, and even images may fail. Instead of convincing its audience of the horror that is cancer, it takes that horror to be self-evident, and bypasses the sense of helplessness in the face of tragedy that we all often face. The audience is empowered to envision a better world, one which he or she can play a part in making. In the process, however, the local context is erased, with sufferers and their suffering completely effaced. If successful, perhaps this tactic will yield more resources for their condition, but to excuse its absurdity with claims of donor appeal is to reduce the problem of breast cancer to one of mere finances.

Adaptability to new techniques of crisis-making can be a determining factor in how limited material and human resources are allocated. Victims often prevail when their suffering is marketed at its bleakest, raising the stakes for all other victims whose stories must be competitively framed. In the meantime, an aesthetic of dismay takes root by which appeal is measured in degrees of shock. After all, "Social suffering is a feature of cultural representation both as spectacle and as the presentation of the real. But cultural technologies now exist to fashion the 'real' in accordance with the interests of power to a degree hardly imagined in the past" (Kleinman 1997: xii). To what extent these "cultural technologies" might be wielded to fashion a "real" that is in fact more real, and how this might benefit the suffering, is a question that emerges as we explore technologies of image-making in the following.

Picturing Suffering: "Crisis" and "Callousness"

For centuries, critics of modernity have decried the consumerization of suffering made possible by ever-advancing media technologies, as well as the associated callousness of audiences hyper-saturated with media representations of that suffering.³ However, as Susan Sontag notes, "People don't become inured to what they are shown-if that's the right way to describe what happens-because of the quantity of images dumped on them. It is passivity that dulls feeling" (2003: 102). We agree that this "callousness" is a symptom not of image overload, but of a lack of effective structures to produce change. As an icon of suffering, a photograph becomes inert. Certainly, it can be used to stir up "moral sentiments" that "mobilize support for social action" (1997: 4), but "witnessing and mobilization... work best when they take seriously the complexity of local situations and work through local institutions" (1997: 8). When they do fail, when witnessing leads to ill-informed mobilizations that do little to exact enduring change, and new images of the same suffering serve simply to replace the old, then "callousness" is the inevitable result. Old tactics must be revisited with increasingly disturbing facts, figures, images and slogans, and new tactics must be constantly remade, in order to heighten the sense of crisis, to shock audiences out of their apathy.

The question then is: Can images obviate the very process by which they are often rendered injurious (or at least inert)? Can they portray "the complexity of local situations," represent the "local context," and in so doing ensure that witnessing and mobilization do not simply leave viewers inured to suffering (Kleinman 1997)? We are not certain that this is fair to ask of photography, limited by its own technology to represent only a minute portion of any given scene. Indeed, the aesthetic value of a photograph is not often measured in its complexity. Rather, a "powerful" photograph elicits a limited range of emotions and does so strongly, not by confusing the viewer, but by directing him or her to at least a few specific questions, if not to specific answers. How fruitful these questions prove to be is largely the prerogative of the viewer, who will decide whether or not (most likely not) to then explore the "local context" of the globalized "local images."

In the field of photojournalism examined in *Social Suffering*, the "photo" is justified and given meaning by the "journalism" portion of its etymology. Captions give suffering a place, and sometimes a name as well. They direct viewers to an ostensibly objective text, where his or her engagement with the image will likely end. The photograph is not presented in order to "contextualize" anything that doesn't already appear in the caption; it is an eye-grabber, either a mnemonic device to revive interest in the subject at hand, or a shock to kindle awed interest in something previously unknown to the viewer. Either way, the purpose is to draw the viewer in, to transform him or her into a reader. And within the text, there are few calls to act, few strategies suggested for the audience to do something about the suffering before them. Witnessing, it seems, is enough. But to what end? That is up to the "callous" viewer to decide.

Of course, this is quite a pessimistic view of photography as a means of representation. Witnessing through photography can, of course, be an active state of acknowledging and affirming others, their pain and their suffering. Perhaps no photographer on a mission to show the pain and misfortune of others was more effective than the photo portraitist Dorothea Lange, who, in the midst of the Great Depression, was hired by the U.S. government to take pictures that expressed what poor farmers were experiencing (Gordon 2009). Her photos, like the iconic Migrant Mother which transfixed an entire nation, documented the crushing defeat that economic catastrophe inflicted on the poor. Lange was told by her supervisors to take pictures of crop failure, erosion, and farm ruin. Unlike them, she understood that it was the artistic portrayal of people in pain, not of destroyed soil, that would offer testimony to what tragic degree rural America was enduring the full force of economic catastrophe. And she succeeded. Her photos transfigured journalism into aesthetics and political influence. So while we may question witnessing and testimony, morally and pragmatically, we have no doubts that at its best, representation can stir hearts and move minds to respond to human misfortune in effective ways. But the images themselves must be captured and disseminated with a caregiver's ethic-a topic we will expand upon in the concluding section of this article.

For now, let us turn our attention to what may appear a more benign medium for representing suffering: the documentary film-or, quite specifically, the charitable global health documentary. It is a familiar though inglorious genre, often funded or at least utilized to promote NGO work abroad. Rarely watched for their pure entertainment value, such documentaries are produced to cultivate and then harness the power of compassion, answering Sontag's (2003: 101) enduring "question" of "what to do with feelings that have been aroused" from exposure to images of suffering:

Compassion is an unstable emotion. It needs to be translated into action, or it withers. The question is what to do with feelings that have been aroused, the knowledge that has been communicated. If one feels there is nothing 'we' can do—but who is 'we'?—and nothing 'they' can do either—and who are 'they'?—then one starts to get bored, cynical, apathetic.

The NGO documentary (or the global health documentary produced to help earn donor dollars) tells its viewers that there is suffering—yes, terrible suffering—in the world. In its purest, most prototypical form, this sort of film will harvest patient testimonials, images of vulnerables, and the authoritative narratives of knowledgeable "experts," usually from the developed world, who can help translate these scenes into a call for action to viewers. "We" can help by visiting a website, making a donation, calling our Congressmen. "We" are told exactly what we can do, and perhaps "we" follow directions. "We" do something, maybe "we" feel good about it. Or do we? When the next documentary is shown, will "we" be more or less likely to donate? What about the next? Are "we" all doomed to apathy, eventually?

This is where Sontag's distinction breaks down. It is not useful to blame the sheer quantity of images of suffering to which viewers are daily exposed as the cause of inaction. But neither is it useful to blame the viewer's "passivity," an inability to take action. That ability is coaxed, asserted, and reasserted, as the popular refrain, "You can make a difference" or, its corollary, "You have made a difference," echoes throughout the aid industry. Rather, it is the reappearance of images, after "we" have been won over, after "we" have made our contribution or done our part in some small way, that renders us "bored, cynical, apathetic." When nothing "we" do is enough, then why bother to do more?

Herein lies one of the greatest limitations of this documentary genre. Although it poses an answer for how "we" can do something with the knowledge given to us by images of suffering, its answer may not always be the one that will see this suffering most effectively addressed. And even if its answer is appropriate, it is often promoted at the expense of "their" agency, reinforcing the notion that there is "nothing 'they' can do." In its pursuit of short-term goals, to raise awareness, garner

support, raise funds, etc., in the simplest and most effective way possible, the documentary may frame out much of the local context, buttressing adverse underlying assumptions as it seeks to convince us that this time, we have no choice but to act.

Consider the video Living With Slim (2004) by Boston filmmaker Sam Kauffmann. Living with Slim is a 28-minute-long series of interviews with seven individual HIV-positive African children, ages 6 to 17. An authoritative female voice issues in English several interview questions, about when and how the child learned of his or her HIV status, how the child reacted, how she or he was treated by family and peers, etc. The subjects are often shy, responding wide-eyed, in a low voice or with tears streaming down their cheeks. Many have lost their parents to the disease and are living in poverty, struggling against stigma and lack of resources Most do not have access to adequate drug regimens. But all have big dreams for the futuredreams that the audience yearns to see fulfilled. This is a moving documentary, certainly; as the Boston Phoenix exclaimed: Living with Slim does its job" (Peary, 2004).5 And it does it well. Screened by the Clinton Foundation at a London AIDSfundraising dinner, the film helped gross several million dollars in donations in a single night. All of the surviving children (one, we learn in a postscript, died six months after shooting ended) were immediately provided with full biomedical treatment. Viewers continue to contact Kauffman to make inquiries about the children and how they can support them.

These subjects are extremely vulnerable, placed alone in a room with a foreign filmmaker and their community AIDS counselor-both strong authority figures. Many are without resources, many are sick. And there is the possibility, ultimately fulfilled, of receiving support in their time of need in exchange for participation in this project. Obviously, "informed consent" is not a major concern here. To those who question the ethicality of eliciting children's testimonies, despite the obvious pain caused by the interviews, Kauffmann explains that he believes the benefits far outweigh the costs.⁶

There is something beyond the legal ethics of representation that is disturbing in this film, however–something that speaks much more to the relationship between the viewer and the representation than to the relationship between the represented and their representation (Institutional Review Boards generally seem to focus on the latter). At a talk Kauffman held for members of a Harvard undergraduate course, one student asked the filmmaker why he had chosen to focus only on children. He responded that children don't elicit the same stigma, since they do not generally contract the disease from unprotected sex or drug use. If it is not a child's "fault" that he or she has contracted HIV through parent-to-child transmission, is it somehow the parents'? Are African adults being blamed for the suffering of their children?

In one of the most troubling scenes from *Living with Slim*, the youngest of the interviewees is shown sweeping outdoors with a wicker broom not much smaller than he is himself. Two heavy women sit on the floor in the background, chatting.

We might think them lazy as we follow our little protagonist doing housework that most Americans would not assign to a six-year-old child. We are not privy to their conversation. No translation is attempted until one of them barks at the boy to sweep well or he will be beaten as soon as the cameraman has left. There is little room for humor in the stiff white text of the subtitle; even if she were joking, we wouldn't know. Here Kauffmann is able to illustrate the woes of the little boy, who tearfully mentions in his interview that he is often beaten. But Kauffmann does so at a price. Suddenly his omission of adult testimonials may be read as a vilification of African adults, as they, too, are made to play a role that will elicit our strongest sympathies.

When one of us (G.R.) sat down for a personal interview with Mr. Kauffmann, he explained that he had tried to differentiate between parents and other caregivers within the film. The cross woman was an aunt; the child's mother had died of AIDS. Mr. Kauffmann said he believes that the situation might be different if the children's parents were alive, and that he was trying to highlight the emotional difficulties of orphanhood. The little boy's treatment was taken seriously by staff at the local hospital, who were concerned by the possibility of abuse. Within a local context, this scene serves an educational purpose, as Mr. Kauffmann argued. The film has been used throughout the country where it was shot (the location is never named) in order to teach health workers about stigma faced by HIV-positive children. But global viewers do not necessarily understand that this treatment is exceptional; when the "local" image is "globalized," it can serve to buttress stereotypes that undermine the agency of local actors.

The argument can be made that both children and adults will likely benefit materially from the video, and as such the framing of their local situation is but a means to a positive end. DVDs of Living with Slim are sold with few strings attached; any NGO or other group can screen it to help bolster a cause. But this argument delimits suffering from AIDS to a problem of scarce attention or resources, ignoring the sociality of suffering in which we are all implicated. Many authors have critiqued the globalization of neoliberal economic policies which leave the poor unable to access decent healthcare, and which increase susceptibility to diseases like AIDS in the first place. The adults who did not contract AIDS through parent to child transmission are also victims of a larger order. To promote AIDS as a cause at their expense would be to reify a neocolonial vision in which countries with money can abdicate responsibility for the conditions of the developing world, while self-righteously justifying intervention on the behalf of select others. This arrangement is less beneficial to the world's donors than one might believe. Fundraising goals may be reached, programs may be implemented, but social suffering will endure, and those images that first mobilized us to intervene will simply be replaced by new ones. As long as we fail to let ourselves see the deeper problems at hand, "callousness" will inevitably transpire—and this sensation is by no means as cavalier as it may sound.

"The states described as apathy, moral or economical anesthesia, are full of feelings; the feelings are rage and frustration" (Sontag 2003: 102).

To analyze *Living with Slim* in this manner is admittedly a straw-man maneuver. This film has helped garner attention for an important cause. It has asked audiences to bear witness to suffering and to respond to whatever call for action is tagged onto it. But critical self-reflection reveals that not all good intentions are without negative connotations or consequences. We present this case to complicate the assumed innocuousness of any media that might be able to short-circuit some of Sontag's concerns (that we grow more "callous," and that our interest in suffering therefore turns vulgar, when we are given no constructive means by which to react to shocking images). However, as in the words of Luc Boltanski, to criticize is to conjure a new possibility: "because critique presupposes precisely recognition, albeit implicit, of a possible state of the world which is the opposite of the reality criticized" (1993: 174). Allow us to move from "presupposition" to pure "supposition," to posit that there are in fact ways in which documentary (and other media forms) can constitute what the Kleinmans (1997) have in the past called "a valid appropriation of images of suffering."

The act of image making is not necessarily one of voyeurism, with all its negative connotations, or simply one of narrowing down a story. Other filmmakers working in settings of social suffering, notably David MacDougall, have come to consider filmmaking a process of exploration. He writes, "One of the functions of art, and often science, is to help us understand the being of others in the world" (2006: 1). MacDougall often produces long observational pieces devoid of voice-over and other narrative conventions; this comparatively hands-off aesthetic can either consternate or enthrall. Whether or not one appreciates his more ethnographic documentary style, many working in the media industry might benefit from the attitude MacDougall takes to his work. He continues, "But meaning, when we force it on things, can also blind us, causing us to see only what we expect to see or distracting us from seeing anything at all."

Others have noted the apparent hegemony of meaning that can often lead a film in questionable directions. In Dai Vaughan's *For Documentary*, the author expresses his regrets when he visits the subjects of a film he has been editing and comes to know them:

To the extent that I fed into the images my subsequent knowledge of the characters and location, the film broke down into incoherence. To the extent that it did cohere, it projected a world that repudiated any connection with the people and place as I now knew them (1999: 54).

Vaughan finds that the "real" escapes his footage, in which there exists a particular film that "broke down into incoherence" when subjected to a comparison with the reality of the people and place it represents. We might consider *Living with Slim* to

also be a casualty of this demand, which urges that good films should be those that tell a story with some economy of footage, and that they tell it coherently, with as few repudiations, inconsistencies, and redundancies as possible. But the complex world of AIDS sufferers in Africa is certainly no more coherent than the London flat of Vaughan's two female protagonists. It is the viewer's responsibility as much as the maker's to presume a multifaceted reality, of which the filmmaker can hope to capture only a small glimmer.

As the Kleinmans argued in *Social Suffering*, "We must draw upon the images of human suffering in order to identify human needs and craft human responses," rather than simply to elicit a response (18). But this formulation perhaps posits a distinction between "we," the viewers of images, and those who capture and present them for us. There is immense room within the technologies of image making for creative explorations of human suffering that expose needs and inform responses, if only "we" can remain open to them. This may require that we suspend our expectations of the imagery surrounding global health, that we allow "meaning" to be ambivalent and at times polyvalent, and that we admit to ourselves that any "coherent" story of suffering is likely a false one. There is no reason that the producers, consumers, and subjects of images of suffering cannot work together to render those images archaic, by beginning to address the problems that first fostered their creation. In the remainder of this paper, we consider how the ethics of representation can benefit when image-and word-makers are brought into the fold of caregiving.

The Presence of Absence

Witnessing and testimony are the opposite of silence and denial. In his famous poem on suffering, "Musee des Beaux Artes" (1940), W. H. Auden examines Pieter Bruegel's "Landscape with the Fall of Icarus" (c. 1558), which shows a ploughhorse and farmer walking past the fallen Icarus: "how everything turns away/ Quite leisurely from the disaster" (14-15). Everyone goes about his business, colluding in the silence. There is an absence of acknowledgment, affirmation, and witnessing. There is an absence of presence—no witness steps forward. But that absence is an active way of being in the world: a turning away, a denial. Auden was writing in mid-Century, with the Nazi atrocities and the Stalinist purges in mind, which took place with few willing witnesses save those victims in the setting of fearful collaboration. An entire failure of presence. And so history set the stage for photojournalism and documentary as the ethical regalia of not forgetting, not turning away, of being there for others.

There is something here of importance. Political psychology is required to understand individual and societal blindness. Out of the horrors of total war, genocide, and medical atrocity comes an ethical commandment to witness. It is the Twentieth

Century's response to the catastrophes of its time. No wonder photojournalism, documentary filmmaking, and the ethnographic film have found a popular space for making visible and heard the brutal realities of political and social violence. In this golden age of the visual and the aural, reality has to be seen and heard to be authenticated and legitimized. An experience of paradox, so central to modernity, reveals that while image and sound create the "real," there are multiple "reals," different people's images and sounds, different people's realities, and even different realities for the same person.

Faced with the paradox of the real—namely, that it is multiple and singular; changing not stable; and incoherent and incomplete—ethnographic film would seem to have the responsibility to tell a story that is without beginning, without end, multivoiced and polyimagined. But in fact the ethnographic filmmaker is not unlike the more traditional word-bound ethnographer. The magic (and limitation) of ethnography is that the ethnographer describes and represents what individuals express and practice as if it were the social world. But no ethnographer can actually claim to grasp the social world in all its complexity and multiplicity. Rather what any ethnographer knows is what a small number of close informants and a somewhat wider circle of acquaintances enable her to know and see. What the ethnographer actually knows are individuals, families, and a few networks, yet she generalizes to society more broadly.

This is the very opposite of what the psychiatrist/psychotherapist does. Her interpretive magic (and limitation) is to go deeply into one person's interior with the equally ambitious, though radically distinctive claim to come to an understanding of the self. From this single self (and the few others the psychiatrist knows) the generalization is to all selves. Selves that are understood with respect to certain cognitive, emotional, and behavioral "universals."

What an exploration of images suggests is that both interpretive operations—generalization to the social and generalization to the universal self—are necessarily distortions of the "blooming, buzzing" world (James 1890: 462). They can at best hold a kind of partial truth: the same partial truths that each of us alone and in our circles can (and do) come up with. But because there is no single understanding that can do justice to human experience, we are left with the limitations of words and images.

And this is not the only conditionality that restricts comprehension. Individuals and worlds are also divided, making for an additional limitation of representation. The world, we mean each of our local worlds, is divided between family groups and networks and institutions that contend for power and that constitute distinctive interests. In turn, the individual experiences a divided self: including division between what can be said and what is morally or politically unsayable; divisions between what is personally at stake and what is ethically better, and division between the emotional tug of conflicting desires.

How is the divided self and the divided world best represented? How do film and writing get at these divisions? Here, great fiction has a great advantage. Henry James's *Wings of the Dove* (1948), for example, not only has an extraordinary account of the divided nature of sensibility in its Foreword, but depicts the divided condition of local worlds about as effectively as can be done. All this draws on the particular imagination and creativity of the novelist; what are the ethnographer and the documentary filmmaker to do? Can they get at complexity, incompleteness, and division in human conditions? And are their audiences willing to support their attempts? We see this as the great challenge for the interpretive social sciences and humanities concerned with the representation of reality.

The problem is not only one of how to represent or what to represent; it makes a question, as we indicated in the first part of this essay, of the ethics of representation. The responsibility of the anthropological interpreter of human experiences to her fellow human being undergoing the experience under study is foundational. It is not just a matter of caring for the other(s). That is to say, the research should contribute to the wellbeing of her research subject, whose subjectivity requires, as Emmanuel Levinas put it, that ethics precede epistemology and ontology (1969: 43): to wit, their problems, their suffering, and their human fragility must be met with an ethic of caregiving. This approach is clearly appropriate in medical anthropology, where it is apparent that the researcher can't just witness pain and suffering without acting to help people who are hurt and in trouble. It is our contention that the same ethical imperative must hold for all interpretive research with human subjects. Care must be taken and given. Research must benefit those who are studied. And this holds for filmmaking as much as for ethnographic writing.

Here we argue that documentary film, ethnographic film, and photography must hold some benefit for those who are depicted (though that benefit need not be calculated in aid dollars). That benefit must come from an ethic of caregiving that is explicitly acknowledged as foundational to the project of knowledge generation and interpretation of particular human beings in particular situations. The makers of the photos and the film must see themselves as part of the human condition they are studying, with caregiving of some sort as central to the art of witnessing. Testimony without care is not good enough to warrant intrusion into others' lives. What that act of caregiving means in the actual practice of creating images and meanings is not something we seek to determine in these pages. We can imagine a wide range of attitudes and actions that would qualify as caring for others. And in fact, it is this wide range that makes caregiving a useful concept.

For caregiving, as we have both discovered while caring for disabled family members, means a hundred different things every day. 10 To truly look after the best interests of another requires real *looking*, as well as intelligent action and critical self-reflection. Sometimes, it may even mean letting go, knowing when to step back and let a loved one care for him or herself. And whether we are at our best or our

worst as caregivers, it makes us more human, laying bare the multiplicities of experience and the divided self. When mistakes are made, we have no choice but to acknowledge them, for it is our own responsibility to correct them. We clean up messes, calm nerves, and try to determine sensitive and thoughtful ways to avoid them in the future. To focus on the well-being of another is to evoke a heightened presence, a sense of being and doing in the world.

It is this sort of presence, when the plight of another becomes the plight of oneself, that needs to be affirmed in research practices. Once caregiving has become foundational to image-making and interpreting, the makers and the interpreters can reason their way toward distinctive standards. We seek to emphasize here two aspects of their responsibility: **acknowledgment** that their human subjects require caregiving, and **critical self-reflection** on behalf of both image and word makers and those whose images and words are being made. For we cannot ignore our Icarus any longer. And painting his picture is just not enough

Notes

- ¹ The Kleinmans make a similar observation about the development of the DALY in *Social Suffering*, although it is being remade here by Grace Ryan, who had not read their chapter until after writing this portion of the Introduction. At the risk of sounding repetitive, we choose to include this paragraph because it points to a convergent evolution of thought that has helped both of us to better understand issues of representation in global health agendas.
- ² Stigma has been a major focus in Arthur Kleinman's research on mental illness. See the following: Keusch, Gerald T., Kleinman, Arthur, and Willentz, Joan. 2006. Stigma and global health: developing a research agenda. *The Lancet* 367 (9509): 525-527; Lawrence Hsin Yang et al. 2008. 'Face' and the embodiment of stigma in China: The cases of schizophrenia and AIDS. *Social Science and Medicine* 67: 398-408; Lawrence Hsin Yang et al. Stigma of mental illness. 2008. In *International Encyclopedia of Public Health*, *First Edition*, eds. Kris Heggenhougen and Stella Quah, 219-230. Burlington: Elsevier Inc.; Lee, Sing et al. 2006. Stigmatizing experience and structural discrimination associated with the treatment of schizophrenia in Hong Kong. *Social Science and Medicine* 62: 1685-1696. Also see Corrigan, Patrick. 2004. How Stigma interferes with Mental Health Care. *American Psychologist* 59: 614-625.
- ³ For examples, see the following: Sontag, Susan. *On Photography* (New York: Picador, 1973); and Boltanski, Luc. *Distant Suffering: Morality, Media, and Politics* (Cambridge: Cambridge University Press, 1993).
- ⁴ In *Social Suffering*, the Kleinmans focus on Kevin Carter's Pulitzer Prize-winning photograph of a small, emaciated Sudanese girl threatened by a vulture watching nearby. Although the photograph helped to mobilize an enormous aid campaign for the famine following its publication in 1993, Carter was said to have simply lit a cigarette and watched the little girl continue her struggle to the relief station after taking the photo. The

Kleinmans relate Carter's ambivalent moral position to that of all photojournalists, who can promote moral causes, but must often do so at the expense of the individuals before the camera.

- ⁵ *Living with Slim* has been well-received by critics, and in 2005 it won the CINE Golden Eagle Award for best documentary short.
- ⁶ Nevertheless, for the sequel to *Living with Slim* (now in production), which follows the children into adolescence and adulthood, he chose to secure Institutional Review Board approval.
- ⁷ In a personal interview with Grace Ryan, Mr. Kauffmann explained that he had already had some experience filming children for three documentaries funded by Al Gore, and so this seemed like a "special perspective" that he as a filmmaker could take on AIDS. Nevertheless, in a presentation of his work for undergraduates of the Harvard African and African American Studies course "Making Media Across Cultures," he had emphasized his interest in filming HIV-positive children because of the willingness of viewers to regard their situation favorably, as described in this essay.
- ⁸ In an American culture that has criminalized even spankings, indications of abuse abroad enter theatres heavily loaded.
- ⁹ For examples, see the following: Farmer, Paul. 2005. *Pathologies of Power*. Berkeley and Los Angeles: University of California Press; Lakoff, Andrew, Kleinman, Arthur, and Petryna, Adriana. 2006. *Global Pharmaceuticals: ethics, markets, and practices*. Durham: Duke University Press; Krueger, Leigh E. et al. 1990. Poverty and HIV sereopositivity: the poor are more likely to be infected. *AIDS* 4(8): 811-814. Whiteside, Alan. 2002. Poverty and HIV/AIDS in Africa. *Third World Quarterly* 23(2): 313-332.
- ¹⁰ Caregiving has become a major focus of Arthur Kleinman's current work. See the following: Kleinman, Arthur. 2009. Caregiving: the odyssey of becoming more human. *The Lancet* 373(9660): 292-293; and Kleinman, Arthur. 2008. Catastrophe and caregiving: the failure of medicine as an art. *The Lancet* 371(9606): 22-23.

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