

Culture, Mind, and Society

Afflictions

*Steps Toward a Visual
Psychological Anthropology*

***Robert Lemelson and
Annie Tucker***



Culture, Mind, and Society

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To Dorothy Lemelson: With the deepest respect, admiration, and love

PREFACE



Photo 1 Anthropologist Robert Lemelson at a *jathilan* performance in 2006

In 1996, as a graduate student in psychological anthropology, I went to Indonesia to conduct doctoral research exploring the influence of cultural context on the experience and trajectory of mental illness. The question I was interested in, addressed in a series of research projects by the World

Health Organization (WHO) (the International Pilot Study on Schizophrenia and the Determinant of Outcome of Severe Mental Disorders) in the 1970s forward, seemed straightforward enough: why people who have developed a psychotic illness in the developing world have a better outcome or recovery than those in the West. This has been termed “The Outcome Paradox.” How could it be that people living in societies that had few dollars, or national resources, devoted to the care and treatment of people with serious mental illness, like Indonesia, would get better more quickly, than in the West, where large sums are devoted to the care and treatment of people living with mental illness?

The WHO researchers defined outcome as the ability to return home after an initial hospitalization, return to work, and have fewer severe symptoms, re-hospitalizations, and relapses. After engaging in the largest trans-cultural psychiatric epidemiologic research project in history exploring this important public health concern, they identified a number of domains that were related to differential outcome and recovery from mental illness. These included attributional models of etiology for illness, labeling of symptoms and syndromes, the relative flexibility of daily routines; types of treatment available and accessible, the degree and types of social support, and the family emotional climate a patient returns to, among others. However, they struggled to fully answer this question, in part because the clinical and epidemiological emphasis of the research, while being able to identify these important domains, in some ways lacked the textured specificity to parse out these factors, in particular cultural places and times. One of the needs cited for future research in the WHO final report, in reference to recovery factors for schizophrenia in the developing world, was a call for greater integration of ethnographic findings. They called for qualitative and anthropological research to tease out the contextualized specifics.

In addition to “The Outcome Paradox” seeming to be an important and complex question with real life implications, it was this call for ethnographic approaches that I responded to after taking a seminar on this issue with one of my mentors, Prof. Robert Edgerton, who had done foundational work on the relation of psychosis and culture. I picked Bali as a field site, following the suggestion of another of my mentors, Prof. Douglas Hollan, who had extensive research experience on the neighboring island of Sulawesi, among the Toraja.

Bali, Indonesia, is one of the most well-examined societies in the world by anthropologists. For over a hundred years they (alongside the now millions of tourists) have come to this beautiful and culturally elaborate

society to explore a wide range of topics. In anthropology proper, Bali is now seen as a place that is well understood, even overdone, and thus perhaps lacking in contemporary ethnographic interest. However, since I wanted to investigate the impact of culture on mental illness experience, a well-examined culture such as Bali seemed a good fit; there was already ample information about the myriad aspects of the ceremonial, ritual, and social life that might be relevant.

To conduct such a study I knew I would need to explore such diverse areas as explanatory models, local ways of understanding unusual sensory experiences, cultural shaping of putative psychiatric syndromes, and traditional and biomedical/psychiatric treatment systems. My conceptual toolkit included participant observation of locally available treatments; utilizing etic models such as psychiatric nosological and diagnostic systems to separate symptom and syndrome, disease and illness; and exploring the lifeworlds and life histories of my subjects via in-depth interviews. I also planned to use clinical and ethnographic forms of data collection including culturally contextualized diagnostic interviews; structured, semi-structured, and open-ended interviews; person-centered interview schedules; and community and clinical surveys. In my dissertation proposal, I briefly mentioned that I was interested in videotaping some of my research.

I was lucky at this early stage in my research career (1995–1997) to meet a Balinese psychiatrist, Dr. Luh Ketut Suryani, who had been involved with the WHO research and had done her own sophisticated work on culture and mental illness. In the mid-1980s she had spent a year collecting first hospitalizations for acute psychosis, and had a sample of 115 cases, which she investigated using a mixed method approach of clinical evaluation, interviews, and structured questionnaires. After meeting and discussing my interests with her, she agreed to have me work with four of her residents to re-contact these original patients, re-interview them, and do one of the first ten-year follow-up studies in this area. Over the course of a year and a half in 1996–1997, 95 of the original 115 were re-contacted and re-interviewed.

Toward the latter part of this fieldwork I received a letter from a colleague who was a researcher at the National Institute of Mental Health (NIMH), who wondered if I would be interested in participating in a pilot research program at the NIMH attempting to find cases of neuropsychiatric disorders in the developing world. The impetus for this research was the then-recent finding about the pediatric autoimmune neuropsychiatric disorders associated with streptococcus infection, also known as the PANDAS hypothesis. Briefly,

this was a theory that some cases of specific neuropsychiatric disorders, such as obsessive-compulsive disorder and Tourette Syndrome, had their origins in multiple streptococcus infections in children who were genetically predisposed. The research team believed that in a place like Indonesia, with high rates of infectious diseases, it should be possible to find cases of neuropsychiatric disorders, and then link these back to elements related to the PANDAS hypothesis.

After multiple presentations were made to local psychiatric professionals about this research, one of the local psychiatrists, I Gusti Putu Panteri, who ran a private psychiatric hospital in Denpasar, Bali, approached me about collaborating on this project. He had been in practice for decades and had an extensively documented clinical caseload; several dozen of these patients were identified who fit the NIMH criteria. We then spent six months re-contacting these patients in their villages scattered throughout Bali.

Several months into this new research project, a friend and graduate student in anthropology who had some experience in the film world, came to Bali to stay with my family for several weeks. We agreed she would film me conducting my fieldwork. Beyond that, I did not give much thought to how I might use these films.

In the following few weeks, we gathered approximately thirty-five to forty hours of video with a dozen or so of my research subjects. Some of these were truncated interviews shot largely for their visual quality, while others were more complete ethnographic interviews. Upon returning to the United States, I put the videos aside and spent the next year and a half completing my dissertation. While writing, I was contacted by a young Javanese psychiatrist, Mahar Agusno, and his wife, psychologist, and English teacher, Ninik Supartini, who were interested in my research and potential collaboration.

After finishing my dissertation in 1999, I started a project with a geneticist who was exploring various aspects of the genetic basis of common neuropsychiatric disorders. She was interested in finding cases of Tourette disorder in Indonesia. My collaborators Mahar and Ninik assisted us with this project, initially collecting cases drawn from Mahar's clinical case log and then conducting a community-based study to find additional cases by going through villages in Gunung Kidul, a poor region of Central Java where Ninik was from and where many in her extended family still resided. Mahar had just finished his residency in psychiatry, which had required him to serve a large region of rural South-Central Java. This made him the ideal person to do the required community surveys. In late 1999 and early 2000,

they conducted a detailed survey of several regencies. Mahar and Ninik videotaped some of their subjects for research purposes. The genetics project soon foundered due to a lack of funding, but the anthropological project, which was a logical extension of my work in Bali, continued.

At this point, I also began teaching at UCLA, and I thought about the thirty-five to forty hours of film footage gathered in 1997. Around the same time, a young documentary filmmaker approached me, to give my anthropological opinion of a recent film he was directing. I thought the material and his approach interesting, and asked if he was able to work with me on editing the footage I had into small teaching pieces, for my classes. He agreed, and we produced several short videos. They turned out to be a big success with my students, and I decided to go back to Indonesia, re-contact the people in the footage, and follow them up, both for research and to expand upon the teaching films.

In the summer of 2000 I therefore returned to both Bali and Java. In addition to the young documentary filmmaker, I worked closely with Wayan Sadha, a cartoonist and journalist who provided an indispensable lens into the daily life of the average Balinese, and later with his daughter Sri. Unfortunately my collaborator on the neuropsychiatric research, Dr. Panteri, had had a stroke in 1999, making collaboration difficult. I was also able to work with Dr. Made Nyandra, a much younger Balinese psychiatrist “on his way up.” As a Christian, Dr. Nyandra offered some interesting perspectives on the dominant Balinese Hindu community. In Java, my initial collaboration with Mahar and Ninik deepened into what became my closest and most longstanding professional relationship and friendship in Indonesia. I discovered that Mahar was deeply interested in the interplay between Javanese and Indonesian culture and the experience and outcomes of the people living with the different forms of mental illness he was treating on a daily basis. Ninik, as a psychologist with an interest in cultural psychology, provided great insight into many different aspects of Javanese culture.

In these early years, however, my understanding of film and filmmaking was still rather minimal. Having grown up on a television diet of documentaries made in the 1960s and 1970s, ranging from Mike Wallace’s *Biography* series, to the Mutual of Omaha’s *Wild Kingdom* and *National Geographic* specials, I had a very naïve understanding of just what good cinema or good documentary, let alone good ethnographic film, entailed. As an undergraduate and graduate student in anthropology I had been exposed to the typical if rather sparse set of classic ethnographic films, from John Marshall’s

The Hunters to Timothy Asch's *A Man called Bee* and *The Ax Fight*; a range of other ethnographic snippets, typically focused on some aspect of technology, subsistence, or ritual life; and the occasional more complex film, such as *Ongka's Big Moka*. But my understanding of films was largely gained through watching and discussing them with my friends, and through the general diffusion of knowledge that permeates life in Los Angeles, where so many work in the film industry.

At this early stage, in 2000, I did not foresee the visual ethnography becoming extended beyond short teaching pieces. I simply hoped that if I could visually document the lives of my participants, this might bring my students into the world I was immersed in as an ethnographic researcher. Accordingly, as I traveled in Bali and Java continuing my ethnographic explorations of culture and mental illness, I saw the camera as little more than "an extension of my eyes," recording my ethnographic encounters while documenting the rich cultural life of the communities in Bali and Java.

In the following years, my experience, ambition, and love of filmmaking grew. I returned to Indonesia every year once or twice a year for two to four weeks at a time to continue this work. In the intervening months, footage would be edited and assembled into basic narratives; as I first began making teaching films with the materials shot, I designed the structure of the films around key research topics of interest in the field, such as cultural differences in the symptomatology and expression of illness, rather than around individuals or their personal stories and what was of primary interest to *them* in their lives. Yet, through filming subjects on repeated trips, I developed deeper relationships with the participants. Through these relationships I began forming a new understanding of the issues brought to the field with research question and hypotheses; ultimately, I realized that the footage collected was full of interesting *personal* stories, and that these stories eloquently articulated not just themes of my original research but wider issues in psychological anthropology.

With each successive shoot, my interest in film and filmmaking deepened and widened. Over the next five years or so, I began to read more extensively about film theory, the history of ethnographic film, explorations in storytelling, narrative, and character development, and many of the related technical issues involved in contemporary filmmaking. My understanding of what "good filmmaking"—and more specifically, good storytelling and good narration—entailed became more informed and nuanced.

Much has been made of the "Cambridge turn" in ethnographic film, and certainly a number of visionary filmmakers and anthropologists have come

out of the Boston area. Los Angeles is much less known as a center for ethnographic filmmaking. This is somewhat odd, as UCLA has an esteemed anthropology program and a famous film school, while USC has the visual anthropology program initially founded by Timothy Asch, which remains a rich source of young ethnographic filmmakers. Outside of these centers for training in ethnographic film, Los Angeles is also of course a global center of the film industry. Yet relatively few, if any, anthropologists have turned toward the film industry here as a resource or a source of knowledge, let alone inspiration or collaboration. In any case, it was not difficult for me to find thoughtful professionals in the film industry with an interest in ethnographic film; some had taken courses in anthropology or even had degrees in visual anthropology. Independent filmmakers in particular can share concerns with anthropologists, committed as they often are to “telling the truth,” about the difficulties of contemporary life and including the voices and stories of those not included in mainstream films.

In 2006 I founded the documentary production company Elemental Productions, and have finished over a dozen films: *40 Years Of Silence: An Indonesian Tragedy* (2009) about the long-term effects of the 1965–1966 mass killings; the six films in the *Afflictions* series (2010–2011); *Jathilan* (2011), a film about possession performance; *Ngaben: Emotion and Restraint in a Balinese Heart* (2012), addressing the personal experience of funerary ritual; *Standing on the Edge of a Thorn* (2012), a film about the complicated pathways to sex work implicating personal vulnerability and social response; *Bitter Honey* (2014), a film about polygamy and gender-based violence in Bali; and finally *Tajen* (2015), on the Balinese cockfight, and other audio-visual projects, with additional projects in various stages of pre-production or production.

In 2009 I hired a graduate student, Annie Tucker, as a research assistant and writer to help develop study guides for the films. Annie received her PhD at UCLA in 2015, researching the interpretation and treatment of autism spectrum disorder in Java; her training in Disability Studies, experience living, working, and conducting research in Indonesia, and her fluent Bahasa Indonesia made her a natural fit as a collaborator. She is the second author of this book.

Through all of this, the project, most longstanding, foundational, and closest to my heart, stems from the original research on culture and mental illness in Bali and Java—the six films of the *Afflictions* series,¹ which are the subject of this book. One of the main purposes of this book is to complement the stories told and themes explored in the *Afflictions* series with both

a deep dive into a written ethnography and more practical guidelines about filmmaking in general. While there are often linkages between ethnography proper and ethnographic film on the same subject, works that specifically link the two are quite rare. Even rarer are efforts to not only connect these two but to provide descriptive, reflexive accounts of the projects themselves, and the related issues of film production, issues of ethics and participant/collaborator/team relationships, and finally to advocate for film as a potentially equal partner to classic ethnography.

This bringing together of ethnographic film and the concerns and domains of psychological anthropology we term “visual psychological anthropology”.

One of the stated goals of a visual psychological anthropology is the rendering of textured, person-centered life history narrative that instantiates these elements into a multi-sensory expression that feels “lived” to the viewer. Another is to connect the domains and the theory in psychological anthropology to the actual lives of participants in our research, and embed these in understandable and emotional stories. Tracking these themes and story, over time, is also key. Linking the visual aspect to the written work, so that each complement and add to each other, further strengthens this new endeavor. Integrating the visual, whether whole films, scenes and clips, or related material, with the written in an interactive digital format helps bring together the fields of ethnographic film and psychological anthropology. Another, more distal goal is to make the research of psychological anthropology available to a much larger, public audience, through the medium of film. This book attempts to address all of these issues.

NOTE

1. The films are available, for a discount to purchasers of this book, at www.elementalproductions.org

SERIES PREFACE

Psychological anthropologists study a wide spectrum of human activity: child development, illness and healing, ritual and religion, selfhood and personality, political and economic systems, just to name a few. In fact, as a discipline that seeks to draw the lines connecting persons and culture, it would be difficult to come up with examples of human behavior that fall outside the purview of psychological anthropology. Yet beneath this substantive diversity lies a common commitment. The practitioners of psychological anthropology seek to answer broad questions about how peoples' inner worlds are interwoven with their outer ones. And while psychological anthropologists may focus on emotions or human biology, on language or art or dreams, they rarely stray far from the attempt to understand the mental and physical possibilities and limitations that ground human experience.

Afflictions: Steps Toward a Visual Psychological Anthropology is a companion to the *Afflictions* film series, six ethnographic films about the experience of mental illness in various cultural settings in Indonesia. In proposing visual psychological anthropology, the authors introduce a sub-discipline centered on the implications of film for theory, ethnography, and the lives of the subjects who anthropologists study. As in much anthropology, the present book works simultaneously on two levels. The chapters here reflect both on the films in the series and on broader questions about ethnographic film, anthropology, and the practical and ethical implications of films that depict mental illness. The authors are attuned—among other issues—to the humanizing possibilities of films that remind us that their

subjects are examples neither of a particular culture nor of a diagnosis, but rather that they are human beings with day-to-day lives in families and communities. Overall, these chapters serve to consolidate and welcome a new area of inquiry in psychological anthropology, one that will undoubtedly help to determine the direction of the field in the coming years.

Tulsa, OK
USA

Peter G. Stromberg
Editor of *Culture, Mind, and Society*

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LIST OF ABBREVIATIONS

AAA	American Anthropological Association
ADHD	attention deficit/hyperactivity disorder
APA	American Psychiatric Association
B.B.	Bahasa Bali
B.I.	Bahasa Indonesia
B.J.	Bahasa Java
BGTC	basal-ganglia-thalamocortical circuits
CBT	cognitive behavioral therapy
CD	compact disc
CSTC	cortico-striatal-thalamo-cortical pathways
DER	Documentary Educational Resources
DOSMD	determinants of outcome of severe mental disorder
DSLR	digital single lens reflex
DSM	<i>Diagnostic and Statistical Manual of Mental Disorders</i>
DVD	digital versatile disc or digital video disc
ECT	electroconvulsant therapy
EE	expressed emotion
fMRI	functional magnetic resonance imaging
HIV	human immunodeficiency virus
ICD	International Classification of Diseases
IDA	International Documentary Association
IPSS	International Pilot Study of Schizophrenia
IRB	Institutional Review Board
KPSI	Keluarga Pasien Skizofrenia Indonesia??
KPSI	Komunitas Peduli Skizofrenia Indonesia??
MMAC	Medicine, Mind, and Culture, at UCLA

NAMI	National Alliance on Mental Illness
NGO	non-governmental organization
NIMH	National Institute of Mental Health
OCD	obsessive-compulsive disorder
OK	okay
PANDAS	pediatric autoimmune neuropsychiatric disorder
PCE	person-centered ethnography
PKI	Indonesian Communist Party
PKI	Partai Komunis Indonesia
PKK	<u><i>Pembinaan Kesejahteraan Keluarga</i></u>
PLOS	Public Library of Science
PNI	Indonesian Nationalist Party
PPDGJ	Pedoman Penggolongan dan Diagnosis Gangguan Jiwa
PSE	Present Status Exam
PTSD	posttraumatic stress disorder
RAID	redundant array of independent disks
RSJM	Rumah Sakit Jiwa Magelang
SSRI	selective serotonin reuptake inhibitor
SVA	Society for Visual Anthropology
TS	Tourette Syndrome
UCLA	University of California, Los Angeles
USC	University of Southern California
VPCE	visual person-centered ethnography
WHO	World Health Organization

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PART I

Steps Towards a Visual Psychological Anthropology



Photo 1 Arjuna meditates, beset by beautiful women (From the Mead Bateson collection)

Visual Psychological Anthropology: A Vignette and Prospectus

1.1 THE MULTIPLE AFFLICTIONS OF GUSTI AYU, “THE BIRD DANCER”

Surrounded by her family, Ni Gusti Ayu Suartini sat cross-legged on the front veranda of her house in rural Central Bali. She was being shot on video by a cameraman and interviewed by a foreign anthropologist and an Indonesian psychiatrist. It was the year 2000, and three years had passed since the anthropologist had originally interviewed her. Gusti did not look well. A baggy red t-shirt swallowed her slight frame and her hair, which had once been shoulder length, was shorn, practically down to the scalp. Her forehead and arms were covered with scabs. At times seeming shy but curious and other times looking down at the floor despondently, Gusti began to tell her story to the small research team and film crew, as her family chimed in.

Gusti looked self-conscious and uncomfortable as her siblings urgently described how Gusti shouted dirty words, seemed compelled to hit herself, moved her body in strange ways, and most troubling, frequently spit copious amounts of saliva. The neighbors called her crazy, possessed, or cursed. Her mysterious illness was embarrassing to her family and shamed them deeply. They believed Gusti had damaged the family’s reputation, hurting their own chances of finding marriage partners, and brought financial misfortune. Quietly, Gusti asserted that she had no control over her behavior, but she joined her family in begging for a cure. Even though Gusti had been formally diagnosed with Tourette Syndrome by a respected Balinese psychiatrist several years previously and prescribed medication, she and

her family struggled with what her disorder meant and how to respond to it, and desperately wished it would just go away.

During follow-up ethnographic fieldwork and videography over the course of many years, Gusti continued to struggle, sometimes saying that she felt she was disgusting and even asking for help committing suicide. As time passed, however, and she continued to search for satisfying explanations and effective cures for her disorder, she also began to distance herself from the social environment that excluded, rejected, and devalued her. Gusti left her natal village and established friendships with peers who were not bothered by her symptoms; she gained self-confidence and self-worth; she found work. Her life began to change and she had ongoing conversations, both on- and off-screen, about these changes.

Almost two decades after she first joined the research and filming project, in a smart white blouse, Gusti set out from her hotel room in Indonesia's capital city of Jakarta, making her way through a bustling landscape of escalators, taxicabs, and skyscrapers toward a packed screening room on the campus of the illustrious University of Indonesia. Together, Gusti and the audience of students, professors, clinicians, counselors, and community members watched *The Bird Dancer* (Lemelson 2010a), a film about her life that located her struggles not just in her bizarre symptoms, but in her social world. After the screening, Gusti sat on a panel for a Q&A session. With a firm voice that still showed a hint of her original shyness, Gusti used a pointed metaphor to describe how she believed prevalent attitudes toward people with neuropsychiatric disorders and mental illness could be re-oriented. She said:

Let's say you have eight eggs, and one looks rotten from the outside, but on the inside this egg is actually just fine, not rotten at all, then how do you solve this problem to make sure you don't throw it away by mistake? Because the owner of this particular egg really cares about it.

In a person-centered interview in 2009, Gusti sat in the hot Balinese sun, in a friend's courtyard, and talked about her life and its recent twists and turns. Gusti had made several good friends, people she could "share her heart" with (B.I. *mencurahkan isi hati*). She said:

If I think about it, now it seems better, because I found work and so I'm free from the house. I wasn't so happy at home, often hearing things from people in the village, you know, insulting me. Now I have a job here, I have many friends. I'm so happy.

At this point, Gusti had been involved in longitudinal visual ethnographic research on mental illness and neuropsychiatric disorder for almost twenty years. This project was an experiment in what could be called visual psychological anthropology, an effort to bring the topics and insights of psychological anthropology to bear upon ethnographic film. While the research team and film crew were working toward developing this approach, Gusti had been filmed going about her daily tasks, having painful and contentious discussions with her family, addressing existential and spiritual concerns about her life and her condition, daydreaming about finding a true love, and growing into her new identity as an activist for people with Tourette Syndrome and other neuropsychiatric disabilities. Representative moments from parts of her entire adult life had been captured on film and edited into a feature-length visual ethnography which has been screened not only at the event in Jakarta, but first privately for Gusti and her immediate family, then her village community, Indonesian mental health advocacy organizations, universities, conferences, and film festivals in Indonesia, the United States, and beyond. The changes in her life have been profound, as she transformed from a depressed and outcast teenager into a self-assured and self-advocating woman.

This impact on Gusti’s life would probably not have resulted from participating in a standard written ethnographic project that could be written, read, and disseminated without her participation, understanding, or input. Nor would the film have become what it was—or reached such a wide audience—without learning with and from Gusti about her life and following her lead as to how it should be represented on-screen. She was an active participant in shaping the evolving understanding of her story, quietly but emphatically moving away from an early narrow focus on her symptoms to a much more complete investigation of her compelling life concerns. The experience of filming Gusti taught invaluable lessons about developing relationships with subjects, understanding their life histories, and representing their stories in a sensitive and empathetic manner. The collaborative and bidirectional process of shaping this initial film about Gusti was a powerful experience, and—because of the visual element—one for which there were few precedents in psychological anthropology, but the process revealed much about the practice and application of the discipline. To most fully understand not only Gusti’s subjective and inflected reality but also how this was both influenced by and influential to the *Afflictions* film