

## Kites and Monsters: Continuity in Cultural Practices



**Photo 9.1** Wayan Adi Yoga Suwarduana

### 9.1 STORY SUMMARY

Wayan Yoga is a young Balinese man in his early twenties. He is pleasant, energetic, and unself-conscious, with many hobbies and interests including cooking, drawing, and the traditional Balinese arts of music and dance. He lives in the same patrilineal family compound where he was born, maintains

a bustling social life, and is actively dating while planning his career as chef on a cruise ship or at a hotel. Wayan has TS, but he seems to barely notice it; both he and his family de-emphasize its role in his overwhelmingly positive and normative young adulthood, instead demonstrating how the stability and continuity of loving family support has bolstered him through his childhood and adolescence.

Wayan Yoga was born in urban South Bali, the elder of two boys living in a warm and lively extended family compound. From a very early age, Wayan Yoga exhibited an interest in the arts. As a young child he was captivated by the monsters of Balinese mythology brought to life onstage in village theaters and folk storytelling practices and enjoyed drawing pictures of these creatures and dancing out the action of these dynamic tales. If not drawing or dancing, he could be found fishing or flying kites with the other boys from the neighborhood.

When Wayan was about four and a half years old, his family noticed he was blinking frequently and severely, and repetitively yelling out “dirty” words and phrases such as “bitch,” “fuck,” “cunt of the dog,” and so on. He would also flex and release his stomach muscles in an exaggerated manner, and he seemed to have difficulty focusing his attention. He had become deeply interested, in a way not shared by his young friends, with the monsters, giants, and other terrifying creatures from Balinese mythology, talking about them all the time and describing bloody battles between them and humankind. The family was concerned and uncomfortable with his behavior, in particular with his shouting of inappropriate words, so his father took him to see the doctor on staff at the hotel where he worked. The doctor prescribed some medication, which did not have a marked effect. The family then took Wayan to a traditional healer, but Wayan’s condition did not improve after this visit either. His father called a family meeting and after consulting with the group, decided to pursue further medical treatment with a specialist. In doing so, he found Dr. I Gusti Putu Panteri who did an initial evaluation. He diagnosed Wayan with TS and ADHD and prescribed a low dose of Haloperidol, an antipsychotic medication that is a front line treatment for TS in Bali.

Dr. Panteri presented the neurobiological model of TS to the family, explaining to them that Wayan’s behaviors were to a great extent out of his control, but that he was otherwise perfectly normal and healthy. Dr. Panteri explained that there were other Balinese people with TS, and he counseled the family not to get angry or upset at Wayan, not to think of him as “naughty” and not to worry about him too much, but to support him and

to become an advocate for him when necessary, encouraging them to educate others about TS. Once Wayan entered elementary school, the family did in fact explain his condition to his teachers and peers so that he would not be stigmatized or punished in school. They also adhered to the pharmacological regimen prescribed by Dr. Panteri, monitoring Wayans intake of Haldol.

As he grew, Wayan continued to experience symptoms as the disorder progressed, in parallel to brain development and maturation. When he was eight, he was regularly taking his medication but continued to display occasional bizarre movements and still had difficulty focusing for long periods of time. However, his parents remained convinced that his encounter and treatment with the psychiatrist had been a turning point in Wayan's behavior, after which he more or less continued to do well. His relationships with his peers were normal and he still enjoyed flying kites and drawing. The family took every effort to include Wayan in family activities, and if it seemed that he was isolating himself or seemed to be in a dissociated state of consciousness, they would try to engage him.

By his middle adolescence, Wayan was still occasionally experiencing new symptoms—he no longer moved his stomach or shouted out inappropriate words but would flap his arms and jiggle his hands, especially when he was relaxing watching television in the evenings. Due to changes in the family's economic situation, they could not afford the prescription medication for Wayan but were using Chinese herbal medicine and felt that it had a positive effect. Wayan seemed not to have internalized any negative feelings about himself due to his movements, maintaining an active social life; indeed, because his peers and family members were so used to his movements, they didn't pay much attention to them. Wayan, confident in his emerging manhood, said that if anyone dared tease him about these movements that were out of his control he would knock them about a bit to teach them a lesson. He seemed to naturally grow out of his childhood over-involvement with demons and monsters, although his affinity for kites had deepened, and he was now making his own, which were quite beautiful.

After he graduated from high school, Wayan attended culinary school in order to get a job on a cruise ship as his cousin had done, a job that can be quite prestigious in Indonesia because of the relatively high salary. If that did not work out, he planned to work in a hotel like his father. After initial nerves about attending school, Wayan reminded himself that if he put his mind to it, he could achieve anything, and now he feels confident preparing various meals. His family currently describes his symptoms as in almost total

remission, only emerging when he feels stressed, despite the fact that he is no longer taking any medicine. He is actively and optimistically planning for his future as a husband, father, and family man, still passing his free time building kites, drawing, playing music, dancing, and hanging out with his neighbors playing computer games.



**Photo 9.2** Wayan Yoga refuses to be bullied because of his disorder

Wayan's TS has been relatively insignificant to his evolving sense of self when compared to the saturation of symbols, images, and narratives of his culture. Wayan had to learn to negotiate the kinds of movements caused by TS, his levels of interest in morbid matters, and he had to develop goals that were culturally appropriate. The protective buffer of his family guided him successfully into normative Balinese adulthood.

## 9.2 NORMALIZING UNUSUAL MOVEMENTS

Wayan and his family fairly quickly embraced a psychiatric model of TS. At first glance, this model might not seem “continuous” with Balinese culture because it offers a very different etiological view of tic symptoms than is consistent with Balinese explanatory models around etiology. However, in the case of a neuropsychiatric disorder such as TS, a psychiatric perspective

may have provided a sense of stability or continuity, rather than disruption, for Wayan and his family.

In some cases, a psychiatric model of neuropsychiatric disorders might free people from the quest for meaning in their illness experience which, while perhaps counterintuitive, in the case of TS and other disorders such as OCD may in and of itself bring great relief. From an insider's perspective, the movements and behaviors of TS are experienced as meaningless, albeit compulsory. However, the meanings ascribed to them in Balinese healing logic might add layers of distress to the experience, as patients contend with accusations of black magic, fears of having made ritual mistakes, or an internalized sense of being punished, in sum, indicating that something has gone significantly wrong in their social circle and/or spiritual lives. In Gusti's experience, this was clearly the case. Meanwhile, Wayan Yoga's experience attests to the potential benefits of a neurobiological explanation for illness or difference, which in effect suggests that the tic and other behaviors involved in TS are in fact "meaningless," indicating nothing more than a neurological disorder that is unrelated to cosmological order, interpersonal or community relations, or even personal intention or agency.

There also appeared to be some congruity between Wayan's symptoms and Balinese performance culture and gendered aesthetic. First, there were Wayan's obsessions when he was a little boy. His parents reported his obsession with fearsome characters from folklore and mythology, including *ogoh-ogoh*, or monsters, *buta kala*, or evil spirits, and *Rangda*, the Balinese witch. He relished retelling stories featuring these characters and the violence they do to human beings, and often recounted and re-enacted these for local collaborators. Given the previously described co-occurrence with OCD and ADHD, these thoughts should not be considered unusual; OCD often encompasses recurring thoughts of a morbid, sexual, or violent nature, such as hurting others, even though the person with these thoughts would never follow through on this (Bouvard et al. 2016; Wetterneck et al. 2015), while ADHD can be associated with impulsivity and aggression due to disinhibition (Ahmad and Hinshaw 2016). At the same time, folk tales filled with a kind of gleeful violence can be found throughout the world and are often greatly enjoyed by children and adults (and some might even argue these folk tales are cathartic or therapeutic) (Bascom 1954; Johnson and Price-Williams 1996). The content of Wayan's obsessions was to a certain extent both culturally and developmentally normative and appropriate, even though his level of engagement with them was not. As he matured,

with the support of his family Wayan redirected his attention into other culturally available and appropriate activities, such as kite building and dancing.

Even the physical expression of Wayan's tics might have seemed culturally normative. While his family did perceive his physical movements as somewhat unusual and out of place, in and of themselves they also seemed familiar. As opposed to women, like Gusti, who are expected to be composed and decorous, men are allowed a wider range of dynamic physical expression, normatively "active" and "self-projecting" (Parker 1997), and "bolder, noisier, and more 'forward' in their socializing" (Parker 2004, p. 304). Therefore, while it is certainly not normative per se for young boys to shout out curses, it may be slightly less obtrusive, or more likely to be forgiven or overlooked in boys.

As in Gusti's case, performance genres may have also provided a framework of interpretation or intelligibility for Wayan's explosive movements. In contrast to the embodied and expected female habitus of smooth, contained, and gentle movement, both men and male dancers have a freer range of motion, with different permissible and even admirable movement qualities, some of which may be quite explosive and staccato. Like Gusti, some of Wayan's tics seemed to mimic the movements performed in traditional dances, particularly the repetitive inflating and constricting of his stomach muscles and the tensing of his arms bent at the elbow. Indeed when Wayan's father re-creates his son's tics, he could easily be thought to be referencing Balinese dance. In Wayan's case, however, these movements are congruent with the movements of revered male characters, including warriors in the Balinese *Baris* dance and kings in the *Topeng Tua* dance, movements Wayan in fact performs proudly for the camera near the end of the film. Therefore, while his tic movements are out of context, they are not inherently incongruous with a culturally constructed gender identity and hence not in and of themselves devaluing.

Like Gusti was, Wayan is surrounded by and embedded in a rich base of intricate artistic production and cultural forms. These interact with the symptoms of their neuropsychiatric disorder, acting as a central frame of reference for interpreting their physical comportment and expression, both directly and consciously and perhaps unconsciously lending positive or negative value to certain physical qualities or behaviors and embodied gender norms and ideals.



**Photo 9.3** Wayan Yoga, now an adult, continues his artistic endeavors

An emphasis on Wayan’s essential nature that remained unchanged, as a backdrop to what was framed as a comparatively insignificant disorder, may have set up Wayan and his family well to actually allow him to “grow out” of his TS. Research into TS increasingly suggests that it might be a developmental disorder, meaning that it occurs or arises during a particular stage in child development, retarding or interfering with typical development processes. Some developmental disorders lead to lifelong difficulties, but for others naturally occurring developmental processes ultimately mitigate the disorder, and symptoms fall away to a significant extent by the time an individual has reached adulthood. This hypothesis is supported by data gathered in two of the largest fMRI studies of TS conducted to date, which identified age-related abnormalities in frontostriatal networks and in frontoparietal connectivity, suggesting that TS patients are not undergoing typical maturational changes in the brain (Marsh et al. 2008; Church et al. 2009). However, tics and symptoms of TS can often fade once the person develops out of adolescence into young adulthood (Felling and Singer 2011).

In other words, even if an individual with TS receives little in the form of targeted treatment or therapy, over time his or her symptoms may subside on their own. Wayan’s TS indeed seems to have followed this course; while initially the family believed that the prescribed medication was at most

causing and at least supporting their son's improvement, after a number of years they were forced to stop giving him the medication due to financial hardship. His tics seemed to remain mostly in remission, and they believed he continued to improve.

Since the WHO's DOSMD study, much has been made of the protective aspects of culture outside the industrialized West; in the case of Wayan Yoga, family support and a meaningful social role in his community have promoted his positive long-term outcome. His life story embodies the "good" (Robbins 2013) of continuity, which is explored ethnographically within Yoga's family and the matrix of Balinese cultural practices that have buffered his normative development; the idea of "continuity" is also explored as a filmmaking strategy, returning to Wayan's home at regular intervals throughout his childhood and young adulthood, exploring similar topics, such as symptoms, treatment, social experience, and so on, and filming similar interactions, in order to capture the stability and positive growth Wayan enjoyed over the years despite living with a neuropsychiatric disorder.

### 9.3 LONGITUDINAL FIELDWORK AND A CHILD'S GROWTH

Wayan Yoga's case is unusual or even an outlier in the rest of the *Afflictions* series. For one, it is the only story that involves a young child, although through the course of the film the young child grows into a young adult. This raised some issues, particularly with regard to consent; a five year old is unable to give full consent and this could be ethically problematic. Because Wayan's parents understand that the lead author is a researcher affiliated with their psychiatrist (Dr. Panteri), they gave us permission to film. At that point, in 1997 the plan was that the footage would be solely used for research and teaching purposes, rather than be crafted into an ethnographic film per se. This was explained to Wayan's parents and they readily gave consent. As the project developed over the years and there was evolving use of the material, detailed discussions of this material were held with the family. Once there was a rough cut, Wayan was already nineteen, so consent was discussed with him directly.

With each session of shooting the film there was more supportive material of Wayan dancing, drawing, narrating traditional Balinese mythological and cosmological narratives, kite building and kite flying, and finally playing musical instruments and building his career as a Balinese chef. By shooting



these continuously over the years, it was easy to construct an edited narrative that linked these continuities over time. In addition, the film constructed animated sequences that not only illustrated stories Wayan was telling but also mirrored his development and developmental abilities as a creative young artist.

Wayan's case was unusual in other ways. Despite what could be considered comparatively positive outcomes for many of the *Afflictions* participants, his was, honestly, really the only "happy" story in the series. As in the story laid out in the film, Wayan's development and progression was shaped by these Balinese cultural practices as well as a supportive family, in conjunction with the gender and attribution issues discussed earlier. The story was a counterpoint to the rest of the stories in the series, and pointed out how the right mix of temperament and personality, combined with a supportive family and cultural environment, and additionally supported by an attributional and labeling model that de-emphasized stigmatization, could lead to the overwhelmingly positive outcome shown in the film. It also illustrates that, at least in ethnographic film, one does not necessarily need conflict or great suffering to make a film interesting on its own terms. Interesting contexts, some character development and change, and a degree of emotional resolution can be enough to create a satisfactory and interesting film.

## 9.4 LAST ENCOUNTERS

In our last interview, as seen in the last scenes in *Kites and Monsters* (Lemelson 2011a), Wayan had grown into a self-confident young man, hopeful for his future. He was asked, "When you were little . . . you liked drawing and thinking about evil spirits. . .do you still like them? Do you still think about them or. . .?" He replied:

No, no, but when it comes to Seclusion Holiday month I still make *Ogob-Ogob* of spirits (large paper-mache models for display in the village). I make them with my friends. But no, I do not think much about them.

Asked about his daily routine, he said:

Oh, I come home, and sometimes sleep. I then play video games with my friends, or visit my girlfriends. I have two!

When asked about his future:

Oh, of course I want to have children. How many depends on my capacity (to support them).

And, finally, his TS:

Oh, it doesn't bother me anymore. That was in the past.

As he spoke he was drawing a beautiful Balinese landscape, and at the end of the interview, he gave this to the lead author, much as he had done when he was five, and eight, and fourteen. He agreed to do a dance performance, and play a pleasant melody on the *rindik*, a bamboo gamelan. As we drove away, Wayan could be seen outside trying to get his beloved kites into the air.

## 9.5 THE “OUTCOME PARADOX” REVISITED

In the preface, it was mentioned that the “Outcome Paradox,” or the finding that people diagnosed with schizophrenia do better in the developing world than in the developed world, was one of the reasons that the research that would eventually result in the *Afflictions* (Lemelson 2010a–2011) series was begun.

The six films of part two have provided contextualized, experience-near accounts of some of the factors that are relevant to the differential outcome paradox. The WHO studies were focused on schizophrenia, and three of the films in *Afflictions* (*Shadows and Illuminations* [Lemelson 2010c], *Ritual Burdens* [Lemelson 2011b], and *Memory of My Face* [Lemelson 2011c]) were on disorders related to schizophrenia. The other three (*Kites and Monsters* [Lemelson 2011a], *The Bird Dancer* [Lemelson 2010a], and *Family Victim* [Lemelson 2010b]) focused on neuropsychiatric disorders. Even recognizing the multiple differences in psychotic illness and neuropsychiatric disorders, the factors below contributed to differential outcome for both sets of disorders.

As we can see using the case method approach in *Afflictions*, the question of what factors lead to better or worse outcome for serious mental illness is complex and individualized, and neither the individual variation of personality strengths that can buffer stressors and lead to greater resilience, nor the biological factors leading to predisposition to developing these complex

illnesses can be diminished. But in these case studies, out of the recurring commonalities that contribute to better outcome, almost all are sociocultural, rather than biological or psychopathological.

One of these commonalities is clearly the importance of family environment. *The Bird Dancer* demonstrates a negative example, where the rejecting, critical, and even at times abusive behavior of certain family members clearly exacerbated—if not actually caused—Gusti Ayu’s unhappy condition. The continual stress of these circumstances certainly contributed to the exacerbation of her symptoms, and it could be argued that the stress response system, which clearly was frequently activated, further exacerbated her overall poor outcome in the early years. Also in *The Bird Dancer*, the lack of any local cultural explanatory label that could encompass the symptoms of her disorder, combined with an attribution of witchcraft or sorcery, contributed to her poor outcome.

The comparison with Wayan Yoga in *Kites and Monsters* could not be more profound. Yoga’s very positive outcome is clearly related to a warm and supportive family environment, and the low level of stress further led to a diminution of his overall symptoms. The labeling at the onset of his condition as one of a “nerve disorder” caused a subsequent depersonalizing of the symptoms and reframed the problematic behaviors for the community, leading to positive community reception and little if any social rejection.

The situation in the psychoses-related disorders is somewhat more complex. Again, family played an important role in outcome in all of the three films. It is significant that not only were all three participants—Kereta, Bambang, and Ketut—married with children, but their families were all quite emotionally supportive, accepting their conditions and providing attributional and labeling alternatives. In Kereta’s case, labeling his experiences as “over-involvement with the spirits” rather than a local variant of “madness” allowed him to return to his life and family after he would suffer a negative episode of symptom exacerbation. In Ni Ketut Kasih’s case, while the family and Ketut herself recognized she had a “mental disorder,” their attribution that the illness was caused by “too many burdens” took away the stigma of an illness not only due to disordered biology, but particularly to her life history and life circumstances. This allowed the family to take positive actions to reduce her “burdens” and continue to supply loving, compassionate social support.

In Bambang’s case, however, his internalization of psychiatric diagnoses and labels contributed to his lingering sense of self as damaged and impotent, and almost certainly contributed to negative view of his prospects for a

productive and happy life. This points to the growing influence of globalization in shaping not only the material conditions of the lives of people living with mental illness, but their internal views of themselves and their relation to their illness experience.

Flexible daily and work routines and roles also played a role. Each of the characters in these three films was able to work on their own schedules, or be released from work responsibilities by their families when their condition deteriorated. This clearly reduced the stress on all three and allowed a resumption of a positive work identity when their symptoms allowed for it.

Access to treatment in the *Afflictions* series pointed out the strengths and weakness of both psychiatric/biomedical treatment and locally available traditional therapeutics. In all of the cases, medication at times assisted in diminishing the more severe exacerbations of the illnesses, but always came at some cost. The side effects of the medications that Gusti Ayu took were always too severe for her, and she discontinued all the medication prescribed. Kereta appreciated that the antipsychotic medication made his spirits diminish, but he too chose to discontinue its use. Ni Ketut Kasih's continuous ingestion of antipsychotics has led to her tardive dyskinesia, which she and the family feel can be more stigmatizing than the symptoms of her illness.

Similarly, traditional therapeutics functioned in variable ways. In Gusti Ayu's case, her search for healing caused her to go through numerous healings, which were at times painful, scarring, and humiliating, but did not ever lead to a diminution of her symptoms. Kereta had a very positive experience of social support with a healer, with whom he lived for over a month, but at the end, his wife did not agree with the therapeutics, preferring "the pill" of biomedically oriented psychiatry to the "oil" of traditional therapeutics.

As can be seen by the above examples drawn from the films, when it comes to better or worse recovery, multiple factors interplay in highly individualized ways to create variably textured and distinct forms of adaptation. One conclusion here is that while identifying the broad factors linked to differential outcome is extremely important, at the end each of these will play a somewhat different and distinct role in the lives of patients and their families. It is these distinctions, as filtered through story, narrative, and experiential accounts, that films such as those in the *Afflictions* series have the opportunity to highlight and emphasize not only for the researchers exploring the relation of culture and mental illness, but for the families and communities of those afflicted with these disorders.

## REFERENCES

- Ahmad, Shaikh I., and Stephen P. Hinshaw. 2016. Attention-Deficit/Hyperactivity Disorder, Trait Impulsivity, and Externalizing Behavior in a Longitudinal Sample. *Journal of Abnormal Child Psychology*. doi:[10.1007/s10802-016-0226-9](https://doi.org/10.1007/s10802-016-0226-9)
- Bascom, William R. 1954. Four Functions of Folklore. *The Journal of American Folklore* 67 (266): 333–349. doi:[10.2307/536411](https://doi.org/10.2307/536411)
- Bouvard, Martine, Nathalie Fournet, Anne Denis, Adelaide Sixdenier, and David Clark. 2016. Intrusive Thoughts in Patients with Obsessive Compulsive Disorder and Non-clinical Participants: A Comparison Using the International Intrusive Thought Interview Schedule. *Cognitive Behaviour Therapy*. 1–13. [10.1080/16506073.2016.1262894](https://doi.org/10.1080/16506073.2016.1262894)
- Church, Jessica A., Damien A. Fair, Nico U.F. Dosenbach, Alexander L. Cohen, Francis M. Miezin, Steven E. Petersen, and Bradley L. Schlaggar. 2009. Control Networks in Paediatric Tourette Syndrome Show Immature and Anomalous Patterns of Functional Connectivity. *Brain* 132 (Pt 1): 225–238. doi:[10.1093/brain/awn223](https://doi.org/10.1093/brain/awn223)
- Felling, Ryan J., and Harvey S. Singer. 2011. Neurobiology of Tourette Syndrome: Current Status and Need for Further Investigation. *Journal of Neuroscience* 31 (35): 12387–12395. doi:[10.1523/JNEUROSCI.0150-11.2011](https://doi.org/10.1523/JNEUROSCI.0150-11.2011)
- Johnson, Allen W., and Douglass R. Price-Williams. 1996. *Oedipus Ubiquitous: The Family Complex in World Folk Literature*. Redwood City: Stanford University Press.
- Lemelson, Robert. 2010a–2011. *Afflictions: Culture and Mental Illness in Indonesia Series*. 182 min. Watertown: Documentary Educational Resources. <http://www.der.org/films/afflictions.html>
- . 2010b. *The Bird Dancer*, from the *Afflictions: Culture and Mental Illness in Indonesia Series*. 40 min. Watertown: Documentary Educational Resources. <http://www.der.org/films/bird-dancer.html>
- . 2010c. *Family Victim*, from the *Afflictions: Culture and Mental Illness in Indonesia Series*. 38 min. Watertown: Documentary Educational Resources. <http://www.der.org/films/family-victim.html>
- . 2011a. *Kites and Monsters*, from the *Afflictions: Culture and Mental Illness in Indonesia Series*. 22 min. Watertown: Documentary Educational Resources. <http://www.der.org/films/kites-and-monsters.html>
- . 2011b. *Memory of My Face*, from the *Afflictions: Culture and Mental Illness in Indonesia Series*. 22 min. Watertown: Documentary Educational Resources. <http://www.der.org/films/ritual-burdens.html>
- . 2011c. *Ritual Burdens*, from the *Afflictions: Culture and Mental Illness in Indonesia Series*. 25 min. Watertown: Documentary Educational Resources. <http://www.der.org/films/memory-of-my-face.html>

- Marsh, Rachel, Andrew J. Gerber, and Bradley S. Peterson. 2008. Neuroimaging Studies of Normal Brain Development and Their Relevance for Understanding Childhood Neuropsychiatric Disorders. *Journal of the American Academy of Child & Adolescent Psychiatry* 47 (11): 1233–1251. doi:[10.1097/CHI.0b013e318185e703](https://doi.org/10.1097/CHI.0b013e318185e703)
- Parker, Lynette. 1997. Engendering School Children in Bali. *Journal of the Royal Anthropological Institute* 3 (3): 497–516. doi:[10.2307/3034764](https://doi.org/10.2307/3034764)
- . 2004. Balinese. *Encyclopedia of Sex and Gender* 1: 303–313.
- Robbins, Joel M. 2013. Beyond the Suffering Subject: Toward an Anthropology of the Good. *Journal of the Royal Anthropological Institute* 19 (3): 447–462. doi:[10.1111/1467-9655.12044](https://doi.org/10.1111/1467-9655.12044)
- Wetterneck, Chad T., Jedidiah Siev, Thomas G. Adams, Joseph C. Slimowicz, and Angela H. Smith. 2015. Assessing Sexually Intrusive Thoughts: Parsing Unacceptable Thoughts on the Dimensional Obsessive-Compulsive Scale. *Behavior Therapy* 46 (4): 544–556. doi:[10.1016/j.beth.2015.05.006](https://doi.org/10.1016/j.beth.2015.05.006)