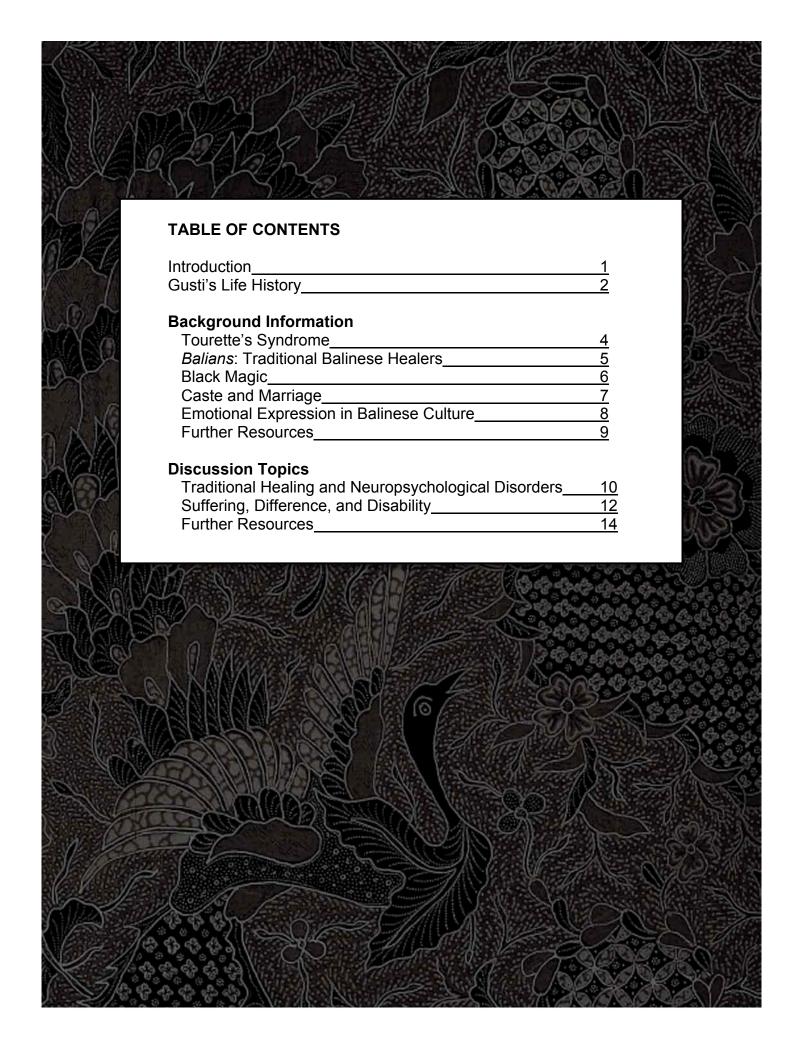
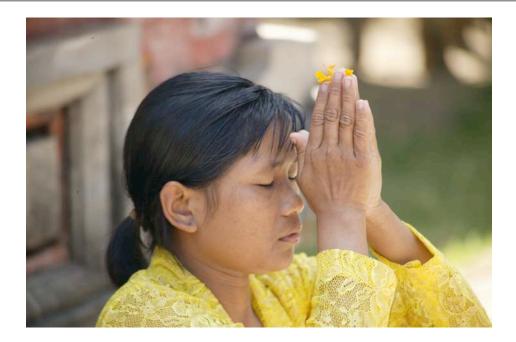


GUSTI AYU SUARTINI
Difference and Suffering in the Context of Culture





INTRODUCTION



Gusti Ayu Suartini is a petite Balinese woman in her early thirties. She was born in a small rural village in Central Bali called Tengkulak to a Kesatria, or higher caste, family. She has one older brother and two older sisters. Gusti attended elementary school and grew up helping around the family compound; feeding the pigs and cows, cooking meals, and preparing the many offerings required for Balinese religious life.

Gusti has Tourette's Syndrome, or TS, a neurological disorder which manifests in uncontrollable physical movements or vocalizations called tics. Tourette's Syndrome was first classified by the French doctor Gilles de la Tourette in the late eighteen hundreds. It is now a fairly familiar, if rare, condition recognized across the globe. TS can be quite distressing for some who experience it, especially those with more frequent or severe tics; however, many people with TS exhibit fairly mild symptoms and are able to pursue typical lives with minimal disturbance.

Totally unfamiliar in rural Bali, Gusti's Tourette's symptoms elicited grave concern from herself and her family, significantly affecting both the daily and the long-term course of her life. Gusti has spent many years struggling to overcome the stigma and suffering that has resulted not primarily from her TS, but from the web of cultural significance spun around it in the context of Balinese values and belief, social and familial structure, and health care practices.



GUSTI'S LIFE HISTORY



Gusti was born in the late 1970's, the youngest of her siblings. As a little girl, she was known for being a bright and diligent child. However when she was nine, Gusti began exhibiting behaviors that seemed bizarre and totally inappropriate for her socio-cultural milieu, such as calling out obscene or shocking words like "bastard dog," and punctuating her normal physical demeanor with strange and twitching movements. These odd behaviors slowly increased and

diversified to include spitting, clicking her teeth, and hitting herself. Her family and community were shocked and had no idea what was wrong with her. Despite her protestations to the contrary, they thought perhaps she was fooling around or misbehaving; she was frequently punished by her classroom teacher, and because of her perceived defiance as well as her family's embarrassment at her condition, in the fourth grade Gusti was ultimately taken out of school.

Over time it became clear to her family that these behaviors were out of Gusti's control. This led to only more worry, however; Gusti's jerky movements looked like those of trance dancers who are temporarily possessed by spirits in certain Balinese dances such as *Manuk Rawa*, or the Bird Dance. Neighbors started to openly mock her by calling her "the bird dancer," and also began to worry aloud whether she had been permanently possessed and therefore was spiritually ill. Others in the village feared that her illness was contagious, and began to shun or avoid her.

Gusti suffered as she moved into adolescence and watched her friends pull away and her family grow more frustrated. Her siblings suffered as well, as the stigma of an unknown illness in the family rendered them undesirable as marriage partners. In the face of these social difficulties, Gusti and her family steadfastly searched for a cure. They consulted with multiple traditional Balinese healers. Most agreed that Gusti's problems were the result of black magic, which is considered a common occurrence in Bali. They suggested that perhaps someone was jealous of Gusti's goodness, and had therefore cursed her. They prescribed all manner of treatments in order to restore her to health, none of which seemed to offer her any lasting relief.

In addition to seeking help from healers, Gusti also consulted a number of psychiatrists and neurologists for a solution to her problems. She was prescribed various pharmaceutical medications, but these were also not a perfect fit as they caused side affects of nausea and excessive fatigue that prevented Gusti from carrying out her everyday activities. These interminable efforts to resolve Gusti's problem, none of which seemed to provide any relief, significantly stressed the family. Her brother accused Gusti of not trying hard enough to "control"

herself, and occasionally imitated and mocked Gusti's behaviors, sometimes even physically abusing her.

A potential opportunity for reprieve presented itself when Gusti developed a romance with a young man in her village. They dated for about three months. He treated her with care and kindness, brought her gifts, and said that he didn't mind Gusti's tics and would help her find treatment. He proposed marriage, and she would have accepted, but he was of a lower caste than her family and therefore her parents forbid the union. Gusti regretfully went along with their decision. A few times in desperation she tried to run away, but her family locked her up to prevent her escape.

In 1997 Gusti met Dr. Robert Lemelson, a psychological anthropologist who was in Indonesia conducting research on Tourette's Syndrome for the National Institute of Mental Health. Lemelson was gathering cases to provide support for the Pediatric Autoimmune Neuropsychiatric Disorders associated with Streptococcal Infections (PANDAS) hypothesis. This hypothesis is based on evidence, initially gathered in the United States, that children who have certain genetic preconditions can develop autoimmune reactions that cause the body to attack parts of the brain, such as the basal ganglia. This can lead to a number of syndromes and symptoms, and the NIMH wanted Dr. Lemelson to find cases that would support or disprove this hypothesis. Over the

course of his longitudinal research, where Rob interviewed Gusti and her family numerous times and accompanied them on trips to healers and medical consultations, they became friends. Rob appreciated Gusti's intelligence and insight but he could also see how desperate and boxed in she felt by her family and community. There were multiple levels of anguish in Gusti's case: she struggled with the symptoms of the disorder and the ensuing frustration of inefficacious cures, but she was perhaps experiencing even more grief from feeling



like a burden to her family. She even reported on multiple occasions that this family dynamic led her to want to kill herself so that her parents could be free of her as the source of their troubles.

Over time, Gusti became certain that to ease her own suffering she would have to establish her own independence. She moved to Denpasar and found a job working as a maid. She made a new group of friends who were accepting of her tics and who encouraged her to accept them as well, to be kind to herself and not to isolate herself from others because of shame or embarrassment. This new situation was a highly positive change for Gusti. She felt proud of herself, and newly confident to be in a situation where she could take care of her own needs without being financially dependent on anyone or feeling like she was a financial burden.



She was happy to be out of the oppressive environment of her village, and with the support of her new friends she was able to develop more effective coping mechanisms to respond to the teasing and stares that she did still at times encounter in the city. She found that the comfort and focus her new life afforded her eased her anxiety, which in turn seemed to lessen her tics, (a commonly observed phenomenon for those with Tourette's Syndrome).

The challenge that persists for Gusti despite her change of milieu and increased independence is her search for a husband and companion. Her longing for love and marriage is simultaneously deeply personal and socially motivated: Gusti wants a soul-mate to share her life with, but she also wants to fulfill her responsibility as a Balinese woman by marrying someone of her caste and bearing children to continue her family line.

TOURETTE'S SYNDROME



Tourette's Syndrome is a neurological disorder that usually appears in childhood or adolescence. It is characterized by the presence of multiple involuntary physical movements and verbal outbursts, known as tics. Visible motor tics can range from small facial twitches to larger full-body motions such as twirling or stamping. Vocalizations may include grunting, throat clearing, shouting or barking. It is commonly known that the verbal tics may often entail the involuntary use of obscenity, or "coprolalia," but this is actually fairly uncommon. In addition to their tics, some people with TS report what is known as premonitory urges, compulsions to perform a particular movement or repetitive thoughts. While the diagnosis of Tourette's Syndrome depends on multiple tics

occurring numerous times a day over the span of at least a year, symptoms can wax and wane, disappear for weeks at a time, or even go into full remission during adulthood. Symptoms most commonly decrease during periods of stress relief or intense focus.

Tourette's Syndrome usually manifests in families with a history either of TS or other associated conditions such as ADHD (Attention Deficit Hyperactivity Disorder) or OCD (Obsessive Compulsive Disorder). It can be accompanied by these conditions, however not necessarily. There are no additional impairments associated with TS, and no inherent barriers to success or achievement for those with the condition. While TS symptoms can range from mild to severe, most people with TS fall into the "mild" category.

Interest and research in TS has increased markedly in the last decade. Once thought of as one of the rarest disorders (incidence of one in a million), TS is now recognized as considerably more prevalent. Some medications, such as Haldol and Clonopin, have proven helpful in reducing symptoms of Tourette's Syndrome. Behavior therapy may also help a person with disruptive tics channel their tics into more socially acceptable actions. Various stress relief therapies, such as biofeedback, also may decrease incidence of tics.



BALIANS: TRADITIONAL BALINESE HEALERS

In her attempts to cure herself of her unwanted tics, Gusti says she has visited so many traditional healers, or *balian*, that she has lost count of them all. This is because for many Balinese people *balians* play an integral role as consultants and healers for all manner of problems.

Balians engage in a variety of activities including treating illness, ministering advice and charms for attracting or keeping lovers, advising and facilitating religious ceremonies, practicing or counteracting the effects of sorcery, and counseling bereaved family members through the channeling of deceased relatives' spirits. Healers are sought for their knowledge and their spiritual power (*sakti*). They call upon various etiological agents and theories of humoral balance, hot-cold dichotomies, biomedical models, possession, sorcery, magic, violations of religious and moral norms including the improper enactment of rituals, and spirit intrusion, imbalance, or disharmony in the patient's environment.



Different balians have different specialties and different goals. For example, balian pengiwa use black or "left-handed" magic to harm, frighten, cause illness or even kill others. However, most balian are balian pengengen, those who practice magic for There are many subspecialties in this healing purposes. category: balian kapican use divine implements to diagnose and treat, and balian katakson channel gods in trance. The highly esteemed balian usada can read sacred ethno-medical texts called *lontar* which are written on palm fronds and bound together into books filled with information about both philosophies of health and practical skills for healing. Balian manak or kampong act as midwives, and balian tulang are known as bonesetters. Balian pengengen may effect cure or counsel through various treatment modalities, such as massage, application of ointment or smoke to the body, ritual prescriptions, spells, herbal tinctures, and etc.

Most balians get their power from a divine source, sometimes even against their will; however it is thought that if a person does receive the calling to be a balian, to refuse would be not only inappropriate but potentially dangerous to the person called, their family, or community. The ability to become a balian may be inherited, or it may be signaled by an episode of sickness and miraculous healing in the balian's own life.

Balians are consulted by people of all socio-economic levels in Balinese culture, from urban government officials to village farmers. Most people consult both balians and medical doctors, and many doctors often refer their patients to balians. The Balinese distinguish between two major categories of illness: those caused by some factor of the physical environment, such as food or weather, and those directly and intentionally caused by another party, whether human, demonic, or divine. Balians may be preferred as care providers because they can address these spiritual



problems that medical doctors cannot, and because they (ideally or theoretically) accept whatever payment the patient's family has to offer, and welcome their patients into their home as a guest.

This is not to say that all *balian* have equal powers to heal. While Gusti's case was perhaps exceptional in the number *of balians* she consulted, it is quite common for Balinese people to switch *balians* frequently, until they find one they feel is truly helping them. All *balians* are not regarded with the same sense of credibility, either, and some do abuse their position. For example, the *balian* who treats Gusti in the film was known for



engaging in questionable ethical behavior, such as taking several of his patients for wives.

BLACK MAGIC

Black magic is a common and familiar, although frightening and unsettling, occurrence in Bali and throughout Indonesia. Indeed, according to Balinese beliefs that envision the cosmos as a system of interwoven and opposing forces, black magic is written into the universe. The balance achieved between these forces is the expression of sacral divinity. Within this system, it is understood tat some are called to black magic, but its practice is still quite frightening and needs to be moderated in order to protect people from its effects.

Some of the most powerful forms of black magic can come from dark spirits known as *roh jahat*, creatures who come from the invisible world. There is another category of being which skirts the borders of natural and supernatural being, known as *leyak pamoroan*, which is often glossed as a witch. *Leyak*s may appear as human, but they are also able to transform themselves into animals or demons, traveling across the island at night.

Ordinary people also practice black magic, often with the help of a *balian*. Black magic can be sent through telepathy, through poisoned food, or in the form of projectile needles, bullets, pins, or other implements. So in the scene where the *balian* says he can feel a bullet inside Gusti's body, he is referring to such an object. Some of the treatments Gusti is recommended, such as hot treatments, massages, or masques, are working under the logic that these ministrations can draw these objects out, dissolve, or move them.

There are a number of reasons why people might be driven to practice black magic upon another person; perhaps they feel wronged and are seeking revenge upon the responsible party, perhaps



they are jealous of another's success and feel the need to restore their own self-esteem, perhaps they want to incapacitate their rivals in economic or romantic competition, or just ensure that events will unfold in the way they desire.



Often, it is the onset of illness, emotional distress, or otherwise abnormal behavior that indicates a person has been the victim of black magic. For example, one commonly recognized behavior that is known to be the result of black magic is *bebai*, which has been described as a kind of hysteria or fit seen in adolescent girls and young unmarried women. Those that are *bebainan*, or experiencing *bebai*, may scream, convulse, or make animal sounds such as quacking like a duck. Another known illness that can result from black magic is paralysis of a limb, known as *lumpuh*, or paralysis of one whole half of a body, known as *mati setangah*.

Considering such pervasive belief in black magic and such familiar physical manifestations of its effects in Bali, it makes

sense how the symptoms of Tourette's Syndrome could be plausibly interpreted as a manifestation of such a black magic attack.

CASTE & MARRIAGE

Up until the present day, Balinese society is organized according to clan, ancestral kinship groups known as *dadia*, and caste. The current caste system in Bali has evolved over time, influenced by indigenous hierarchies of clan, rank and royalty; the presence of Indian traders on the island which some scholars trace back to 900 AD or before; and the caste structure imposed by Javanese Hindus during the Majapahit conquest in the 14th and 15th centuries, which was rigidly enforced during Dutch colonial rule.

There are four main castes in Bali. The largest group is the Sudras, who make up approximately 90% of the population and are generally laborers and farmers. The other 10% are divided into the gentry castes, which include Wesyas, who were traditionally merchants; Satrias, who were traditionally warriors and kings; and the Brahmans who were traditionally priests and teachers. The adherence to the caste system varies throughout Bali, with some groups having a precise and detailed concept of their ancestry, title, and caste position, and others feeling ambivalent about these factors or claiming to have forgotten them.

Nevertheless, this social structure still determines certain aspects of behavior and affiliation for many Balinese people. For example, the Balinese language is divided into three different levels of Low, Middle, and High, and people of lower caste use High Balinese when speaking with those of higher caste, no matter the current economic or professional positions of the two speakers.

People of different castes receive different names and titles; for women, Ida Ayu is the title for women of Brahman caste (such as the Dayu Gusti meets in the film) and Gusti is the title for those of Wesya castes.

Another aspect of Balinese life where the caste system comes into play is marriage. Men are permitted to marry a woman of a lower caste, in which case the woman is given a new title and experiences a rise in status, but women may not marry lower-caste men. Certain women occasionally choose to marry an unsuitable partner despite the proscribed prohibition. If she does this she must leave her home; in pre-colonial times it is said that such eloping was punishable by death, however in contemporary context she may be This context of marriage temporarily ostracized. practices may help explain why Gusti's parents forbid



her to marry a man of lower caste, even though it represented both a chance for love on her part and relief for their family.

EMOTIONAL EXPRESSION IN BALINESE CULTURE

Some viewers of the film may be surprised to notice Gusti or her family members smiling as they speak about sad or stressful matters or when they are in uncomfortable situations. As a caveat, this demeanor should not be interpreted as her family not caring about her situation or as them actively laughing at her. Rather, it may be seen as the expression of a Balinese approach to emotion management. Balinese people generally strive to maintain a pleasing and bright appearance, even in situations where they may be internally experiencing sadness, strife, anger, or physical pain. Their attempts to appear cheerful include laughing and smiling during circumstances where other cultures might find it inappropriate or even rude to do so.

This unfailingly positive appearance embodies a mastery of self-control and a smooth and level personality, which are hallmark cultural values. There is a Balinese word that encompasses these qualities, *polos*, which can mean a number of different things to Balinese people but is commonly glossed by scholars to indicate a uniformity or lack of variation in presentation or demeanor. This smoothness is interpreted favorably to mean that one does not foolishly react to the vagaries of the surrounding environment but rather maintains poise and composure. It is manifested in personal demeanor, interpersonal relationships, but also physical behaviors as well.

Balinese people have been famed for valuing slow and deliberate movements, which illustrate a constant intricate awareness of their spatial orientation with regards to compass directions, key temples and geographical features, and others of different status or standing.





This in part explains why Gusti's tic behaviors were so upsetting to her family and her community; in their jerky unpredictability, they were the opposite of the grace, composure and smoothness of movement that Balinese women work to achieve.

FURTHER RESOURCES

National Tourette's Syndrome Foundation http://www.tsa-usa.org/index.html

Patient Voices: Tourette's Syndrome

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TRADITIONAL HEALING AND NEUROPSYCHOLOGICAL DISORDERS



As mentioned above, healing resources in Bali include both Western allopathic and traditional healing medical systems. If over the last century Western biomedicine has grown in popularity, the practices of traditional healing remain stable and in some rural areas are the only readily available sources of treatment. The system is diverse and pluralistic, with many categories of indigenous healers operating under a spectrum of disease theories.

Some have argued that due to the cultural context they share with their patients, traditional healers are better able to help make meaning out of the "text" of an illness episode than a biomedical doctor, and they are therefore more equipped to cure it. This fits well with anthropological notions that exploring a culture's explanatory models, structures of meaning, belief systems, and so forth, will generate a meaningful and efficacious way to look at illness experience.

Traditional healing can be at least as effective—and frequently more so—than modern medical and psychiatric approaches for a variety of disorders, including mood disorders, psychosomatic and somatoform syndromes, acute or reactive psychotic states, and alcohol and drug dependence. In many traditional healing rituals, patients' experiences are restructured through a culturally validated system of symbols and meanings; the perceived etiological act, agent, or person is identified and a course of remedial or protective action taken. This naming process has significant therapeutic aspects and often causes symptom remission by itself.

Given its often-salutary result, shouldn't traditional healing be more efficacious at relieving the suffering of people with TS-like symptoms? The assumption in medical anthropology has been that cultural meaning systems provide the basis for framing and interpreting all forms of experience, including psychopathology, and that this meaning construction is inherently therapeutic; but what if instead, they are able to provide an understandable meaning for patients, but these meanings have no efficacy? It may be possible that traditional explanatory models for illness provide an understandable and integrated system of meaning for these disorders and yet are not successful in providing symptomatic relief, let alone cure.

The most obvious reason for the lack of efficacy of traditional therapies for neuropsychiatric disorders would seem to stem from the neurophysiologic basis of these conditions. Traditional healing, while interpreting and framing these disorders and their effects, does not appear to reach into their underlying neurophysiologic bedrock.

It would seem that for neuropsychiatric conditions, significant improvement would require an alteration of neurotransmitter systems such as that provided through pharmaceutical medications, or an alteration of underlying neural systems. However, the debate over the effectiveness of various therapies—such as psychoanalysis and other Western treatments—and the necessity of medication to affect these neural pathways is still active in the psychological field. Some clinicians and researchers argue that certain non-pharmaceutical interventions, such as cognitive-behavioral therapy, can be quite effective in altering patterns of brain activity.

However, there is a significant structural limitation that may negate the biomedical treatment for psychiatric disorders. Throughout the developing world there is trafficking and sales of counterfit medication. Indeed, upwards of 50% of medications sold openly in pharmacies in Indonesia may be counterfeit. This means that the active ingredients are either present in the wrong amounts, contaminated, replaced by similar acting substances, or entirely missing altogether. It is probable that some of Gusti's negative reaction to her medication was caused by her ingesting these counterfeit medications.



Another potential limitation of traditional healing practices is that it may not be able to provide a fitting model for the sufferer to help him or her frame her subjective experience of the illness. In other words, there may be no local illness categories that fit the types of illness being experienced, or the indigenous explanations offered may not be syntonic with the phenomenological reality of differing psychological states. In some cases, perhaps, the work of making "meaning" may not be the most appropriate response, particularly because for some neuropsychological disorders the bizarre states or behaviors they incur may not be experienced as meaningful per se.

In seeking to understand how different disorders intersect with different explanatory models, we must consider the various perspectives through which these disorders can be understood and interpreted. These include the prevailing cultural models used to find meaning in the symptoms, the opinion of local experts such as traditional healers and ritual specialists, and the consideration of these symptoms and their explanation in light of theories on the nature of Balinese culture and its relation to individual experience. However, extremely crucial is the sufferer's own perspective. While individuals always differ in their situated understandings of symptomatology, we must listen to their own interpretations. In listening we must come to entertain the idea that in the context of neuropsychological disorders the "meaninglessness" of symptoms—of even the most seemingly affective Tourette's tics for example—may be a crucial aspect of their phenomenology. In the case of neuropsychological disorders, therefore, it may be the case that the insights offered by the psychiatric perspective may be an indispensable additional source of information valuable for treating neurological disorders in a cross-cultural context. In certain cases, it may be that models other than traditional healing (i.e., biological psychiatry) can provide a more understandable and useful framework (from the clinician's and the patient's perspective) for both understanding and treating a disorder.



SUFFERING, DIFFERENCE AND DISABILITY



A case such as Gusti's raises compelling questions about the nature of suffering in the context of difference. What, in fact, is the nature of suffering? How much of the pain and despair people feel is caused by processes internal to them, and how much are they affected by their interactions with the social world they live in? Can we separate the suffering caused by physical or neurological impairments from the suffering caused by their interpretation?

Applying disability studies models of physical difference and neurological diversity to this specific context might help us attend to Gusti's experience and perhaps better understand how human variation gets labeled, shaped, and interpreted, and what the effects and choices are for people caught in these webs of significance. Disability studies is a fairly new field that uses many of the strategies of critical gender and race theory to rethink the social, political, and

aesthetic positioning of certain bodies in relation to others. It often uses two interrelated frameworks as a starting point to parse the existence of physical variety from the various aspects of exclusion or marginalization that so often accompany it; namely, the distinction of impairment from disability, and the "social model" of disability. In disability studies, "impairment" is considered that physical or neurological variation which may make some tasks challenging, requiring of adaption or accommodation, or impossible. As such, impairment is considered biologically based and value-neutral; significantly, it is considered separately from "disability," which in the social model is considered a limited, restricting, or devalued social position that results from the negative interpretations of this impairment and systemic barriers to inclusion at work in any given society.

In the film, we see Gusti Ayu meet another woman with Tourette's Syndrome, named Ida Dayu. While Dayu's symptoms were even more severe than Gusti's, her life experience was very different. She had not been stigmatized, either in her family or community; rather, she had been able to complete college, get a job, marry a man who was supportive and understanding of her tics, and create a family with him. While it is unclear exactly why Dayu's trajectory was so different from Gusti's—perhaps because she was from the highest caste, had grown up in a more heterogeneous urban environment that was more forgiving of variation, or simply had better luck with finding an appropriate match and therefore had been less of a worry for her family—it became clear from their meeting that her TS symptoms had not significantly restricted Dayu's life or possibilities. The contrast of Dayu's trajectory versus Gusti's clearly renders the fact that it was not the symptoms per se, but rather the way Gusti's symptoms had been positioned in the context of her family and her village that were so significantly debilitating; in other words, in comparing Dayu and Gusti we can see the sometimes stark contrast of viewing physical difference as an "impairment" versus as a "disability."



The social world she was living in clearly shaped the reaction to Gusti's Tourette's symptoms; views about health, witchcraft, and physical demeanor described in previous sections of this study guide combined with gender roles, caste system, marriage customs, and a rural location to lend a disturbing significance to Gusti's Tourette symptoms when in fact, as described above, they might have been interpreted as "meaningless" or neutral.

Rather than her Tourette's, Gusti was perhaps most troubled by her feelings of worthlessness within her family system and depression as a result of these ongoing feelings. In an interesting corollary note, there is a proven interaction between stress and tic behaviors; often tics will increase in frequency and severity when a person is under stress, and dissipate or even go into full remission when the person is relaxed or focused on a pleasurable activity. Therefore it is possible that the judgment and frustrating quest for a cure was actually exacerbating Gusti's troubling symptoms.

Either way, from Gusti's own perspective, she flourished in her new environment of the city, and while her Tourette's was not cured by moving to the city, much of her emotional distress was. She describes.

"Now things seem better because I found work and so I'm free from my family's home. I wasn't happy at home, often hearing things from people in the village, you know, insulting me like that. Now, I feel very calm. When I'm home and I'm insulted, I get upset again, and I think about my illness."

Gusti further points to her own independence and self-advocacy as a source of satisfaction and pride.

"I'm not allowed to feel ashamed anymore. I work, I can enjoy life. I can buy what I want with my own effort. That makes me happy; I don't need to be dependent on my family – especially my parents. I can buy things without asking them for money. I can manage my own affairs. That makes me happy and proud of myself."

From Gusti's life history it becomes clear that what was actually at stake were issues that went far beyond the bounds of a neuropsychiatric disorder to include issues of acceptance and rejection in her social world and of her desire to find a loving partner and to build a family. This reinforces the point that when engaging in the study of anthropology, even or especially in the context of impairment or disability, the researcher must take his or her subjects' ever-present life concerns and make them the central component of inquiry rather than a peripheral one.



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