

What's in a name? Diagnostic uncertainty and moral experience in a mental hospital in the Tanga region of Tanzania

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“What's in a name? that which we call a rose

By any other name would smell as sweet”

William Shakespeare, “Romeo and Juliet”, act 2, scene 2

“(...) But the label ‘schizophrenia’ is often toxic for those who acquire it. It creates not only what Erving Goffman called a ‘spoiled identity,’ but an identity framed in opposition to the non-labeled social world.”

Tanya Luhrmann, “I'm Schizophrenic!’ How Diagnosis Can Change Identity in the United States.” (2017)

In 1962, the first independent government of Tanzania inherited from previous German and British colonial governments a mental healthcare system in shambles that relied heavily on traditional healers, with few clinics and some missionary health centers (Kilonzo and Simmons 1998). To compensate for the scarcity of medical resources, the newly formed socialist government of Tanzania decentralized medical mental health services during the 1960s and the 1970s. The system relied mostly on the assistance of psychiatric nurses and expanded the reach of psychiatric care. Although health outreach was thus significantly improved, by the end of the 1990s, only 20% of those suffering from mental disorders had access to the newly formed ecologies of care (Schulsinger and Jablensky 1991). Up until now, most psychiatric care in the

country is handled by nurses and clinical officers.[1] The only specialized psychiatric hospitals are in Dodoma (Mirembe), Dar es Salaam (Muhimbili University Hospital), and the Usambara Mountains (Lutindi Mental Hospital). The small workforce trained in mental health and rehabilitation is, therefore, predominantly concentrated in two major cities, leaving rural areas, to a large extent, neglected.

Over the past century, the Lutindi Mental Hospital (Lutindi),[2] located in the isolation of the Tanzanian Usambara Mountains, developed into one of the psychiatric institutions of the highest standards in the country. Today, it is managed by the North Eastern Diocese of Tanzania, which forms part of the Evangelical Lutheran Church in Tanzania (ELCT). At the time of my research, four psychiatric nurses, one clinical officer, and around 60 non-medically trained employees from the nearby villages managed around 100 “patients” (on an average 80 male and 20 female) a day.[3] Because of its reputation, the hospital drew people from all over Tanzania and neighboring countries. However, due to the high cost of admission, the hospital’s services were more accessible to the urban-dwelling middle classes, mostly from Dar es Salaam, Arusha, and Moshi. The majority were Christian and around five to ten percent were Muslim.

This blog piece examines the lived space[4] of Lutindi, where I conducted three months of ethnographic research (November 2017–January 2018) for my MA thesis. I gained access to the hospital through an NGO that handles volunteering and internship placements across the country, among others at Lutindi. Either clinicians or I informed research participants that I was an MA student conducting research on mental health and illness. During the admission and evaluation interviews I was allowed to attend, or during individual interviews, I asked for verbal consent before putting any of my questions. Drawing on participant observation and semi-structured interviews I investigated the role of the hospital in disseminating biomedical models of mental illness and health within the pluralistic medical landscape of Tanzania.

I will show that while biomedical and religious insights about living a “good life” governed the hospital’s moral code, the patients managed to circumvent this code as a result of a process that I term “diagnostic uncertainty,” an apparent lack of focus in the diagnostic procedure. This process ensued a moral double bind: the hospital promised the possibility of a better, healthier life if patients adhered to its moral code, while at the same time remaining mute about the patients’ needs in the moral worlds outside the hospital. Nevertheless, I will argue, maintaining uncertainty through diagnosis during hospitalization also kept patients connected to these external moral worlds.



Main entrance to the hospital. Copyright: Florin Cristea

Lutindi biomedical and religious care

The Bethel Mission from Germany founded Lutindi in 1906. Previously a foster home for children whose parents had been sold into slavery, the missionaries changed it into a psychiatric institution after discussing the lack of such institutions in the country with representatives of the German colonial government in Berlin (Diefenbacher 1985). The Mission remained in charge of the hospital for most of the 20th century. During my time in Lutindi, it still oversaw its activities in collaboration with the North East Diocese of Tanzania, which further guaranteed close ties to Sebastian Kolowa Memorial University in Lushoto, a private university founded by the ELCT. According to Lutindi clinicians, the university was the primary provider of clinical officers trained in mental health in East Tanzania's Tanga district, thanks to its bachelor's program in mental health and rehabilitation, one of the few such higher-education programs in the country. Psychiatric care in the Tanga region, where Lutindi is located, was, therefore, closely intertwined with religious foundations and the history of Christian medical missions. This is not an uncommon occurrence in Tanzania, where religious and private institutions filled the vacuum created by the state's inability to provide medical care for its citizens, from colonial times until today (Dilger 2014).



Picture taken on the Sebastian Kolowa University Campus. The sign reads: "The fear of the Lord is the beginning of knowledge. Prov. 17." Copyright: Florin Cristea

As a result, the expansion of biomedical psychiatry in the Tanga region brought with it not only biomedical knowledge, but also a system of moral values. The connections Lutindi established to the surrounding villages provides a case in point. When the first foster children from Lutindi came of age in the 1900s, they established some of the settlements surrounding the hospital, namely, Bethania, Kana, and Nazareth. Lutindi's connection to the surrounding villages expanded thanks to its church, its dispensary and primary school, and the employment possibilities offered by the hospital. This network did not only link Lutindi to the communities, but also the community members amongst themselves. "We are all relatives here," I was once jokingly told by Edward, a young man working in the hospital's workshop who came from Kunga, a village about half an hour away from the hospital.

In these nearby villages, when I asked outpatients diagnosed with schizophrenia, their families, and neighbors what they believed were the sources of mental illnesses, their answers were consistent with the etiological accounts given by Lutindi practitioners and employees. Most common was the argument that substance abuse (of alcohol, cannabis [*bangi*], and heroin—the main addictions treated in the hospital), along with heredity [*kurithi*] (understood as transmitted by blood) and stress, were the main causes for mental illness. Mentions of phenomena such as witchcraft, a frequent association made by Lutindi patients, was often met with contempt. "You cannot believe in Jesus Christ and also believe in witches. It is not Christian," reasoned Ebeneza, a young male inhabitant of Bethania.

As the life of the hospital is closely intertwined with that of the villagers, a shared moral tissue has been generated over the past century. Due to these connections, the hospital does not only influence the moral values of the surrounding communities, but, especially through its employees, it is also influenced by them. And the shared values do not only come to light in terms of a biomedical understanding of mental health and illness, but also in the role religious life plays in illness outcomes. Thus, improved mental health was understood to be not just a result of psychiatric treatment but also of religious practice. Lutindi staff encouraged Christian patients to maintain their mental stability by not only following treatment, getting sufficient rest, and avoiding smoking and drinking, but also by going to church and leading a moral life in harmony with biblical teachings, as mentored every day during hospitalization at the six AM morning prayer. Thus, patients were expected to acquire explicit moral markers during hospitalization.[\[5\]](#)

Patients were also expected to acquire implicit moral markers such as discarding previously held beliefs and what practitioners framed as “bad knowledge” in terms of illness etiology. I call these markers “implicit” because they rarely surfaced in verbal communication. If patients brought up phenomena involving associations with witchcraft [*uchawi*], devils [*mashetani*], or possession by jinns [*majini*], they were regarded as “still psychotic” in the medical files. Implicit markers surfaced, however, as patients struggled to find a key narrative for a quicker discharge. As a result, they replaced folk etiologies by more psychosomatic explanations. The more time patients spent in the hospital, the more they tended to replace, *uchawi* [witchcraft] with *msongo wa mawazo* [depression or stress], *changanikiwa* [confusion], or *ugonjwa wa akili* [mental illness]. When I discussed these dynamics with the lead-clinician, he was hardly surprised:

80% of Tanzanians are not using modern health services. A lot of people live in villages without dispensaries. When they have a health problem, they go to the traditional healer. (...) We have a different culture, different traditions. Most African people believe in *uchawi* and witches, or demons, or taboos. It is according to their customs. And many times, a traditional healer is closer to the community. If you want to come to me, you need papers. You need references. To visit a healer, you just knock on their door. The first opinion they get is that of a traditional healer.

Accordingly, due to these initial encounters, and because traditional healers are easily accessible in the village and close to the community, patients continue to invoke their explanations for illness during hospitalization at Lutindi and after.[\[6\]](#) Consider, however, the experience of Godlisten, a patient in his late fifties from Dar es Salaam who was diagnosed with schizophrenia and had been in and out of hospitals for more than twenty years:

They [the doctors] help a little. I could not get good sleep. I was using medicine from the

hospital for the sleeping problem. But the problem of dreaming, of bad magic, was more powerful than the medicine. Local medicine [from the traditional healers] helped more with the bad dreams.

When the symptoms were not clearly related to the body, biomedical treatments were of little help for Godlisten. Despite repeated and prolonged interactions with Lutindi and other biomedical institutions, such explanatory tensions were not uncommon. In what follows, I propose an explanation for these tensions.

Medical pluralism in Lutindi Mental Hospital

Due to my low proficiency in Kiswahili, it was challenging, especially during the first few weeks of my fieldwork, to conduct detailed interviews with patients who did not speak English. Therefore, with the consent and assistance of Lutindi clinicians, I asked two questions at the end of clinical evaluation and admission interviews. I usually inquired about the name and causes of the illness. This led to discussions that were at times marked by disagreement. Clinicians, for example, preferred the term *sonona* [approx. grief] over the term *msongo* [depression or stress] used by patients and their families. Most of the time, however, my questions were met with a shrug. For example, when a man came to admit his wife, instead of answering me, he redirected my question to Dr. Mkiwa, one of the senior clinicians. The doctor similarly suggested *sonona*, but then had to explain the unconvincing diagnosis to a puzzled husband as a “pain in the heart” or “sadness.”

Nonetheless, I witnessed few such exchanges of the diagnosis being discussed with relatives or patients, and, most of the time, they were triggered by my questions. The answers I got during clinical evaluation interviews mostly related to biomedical models. However, in their conversations with me, many patients associated their affliction with non-biomedical etiologies. A few exceptions notwithstanding, they had all visited traditional healers [*waganga wa kienyeji* or *waganga wa asili*], healers [*waganga*], or shehe (the title given to Qur’anic teachers) and argued that their suffering was caused by witchcraft [*uchawi*] or, if they were Muslim, possession by *jinn*s (malevolent spirits). Often, mental illness was not a condition dissociated from these explanations, but a consequence of them.



Interior yard of Lutindi hospital. The patients who showed signs of stability were allowed to leave the wards and walk around on the hospital's premises. Copyright: Florin Cristea

In contrast to practitioners, patients used etiologies that were dependent on the different institutions they encountered during their diverse therapeutic paths that ultimately led into the hospital. The reasons why someone would have decided to use witchcraft or enable an act of possession against a person, ranged from envy [*wivu*], disputes over properties, through to revenge for what a person (or his ancestors) may have done to cause another person's harm. Patients often considered the symptoms that clinicians saw as proof for a mental disorder a reflection of someone's malevolence and ascribed them to failed social relationships.

How to account for this plethora of explanations that circumvented Lutindi's moral code? Exploring diagnostic practices in the crowded city of Lucknow, India, Amy June Sousa (2017), calls attention to the "lack of diagnostic focus" in the communication between psychiatrists and patients. As a result of an insufficient number of psychiatrists and limited time they could allocate for examinations, patients were not told the name or the consequences of their disease. Sousa defines this phenomenon as "diagnostic neutrality" (ibid., 43) and argues that because of it, the biomedical model used by the medical professionals in her study did not interfere with other explanatory models (ibid., 55). Andrea Buhl (2017) identified a similar phenomenon in a cancer ward in Dar es Salaam, Tanzania, describing doctors' "non-disclosure" as a way of maintaining patients' hope in the face of a potentially terminal disease.

I argue in this piece that both "diagnostic neutrality" and "non-disclosure" are one-sided, attending only to the attitude of practitioners. These approaches neglect that practitioners can

withhold information only as long as patients and their relatives do not inquire about the illness. A more inclusive concept I propose instead is that of “diagnostic uncertainty.” In biomedicine, diagnostic uncertainty is commonly understood as the “subjective perception of an inability to provide an accurate explanation of the patient’s health problem” (Bhise et al. 2018, 103). Nonetheless, this latter definition is also conceptualized solely around the experience of practitioners. In the following section, I will suggest a conceptualization that is more inclusive towards patients and their relatives.

Constructing diagnostic uncertainty

In his seminal work about the importance of knowing and not-knowing in medical cultures, Murray Last argued that under certain conditions not-knowing and not-caring-to-know can be part of institutionalized social processes (1981, 387). These processes need to be anchored in medical constellations in which multiple medical systems converge and in which not knowing about affliction comes as a result of a combination of secrecy, uncertainty, and skepticism (ibid. 391–392). Susan Reynolds Whyte (1997) dealt extensively with the processuality of not knowing and the uncertainty of affliction in Eastern Uganda. She suggested that sickness always bears a certain degree of uncertainty and that people’s ability to experiment with alternative therapies can represent an important resource for dealing with this uncertainty (ibid. 23). In her field site, this ability contributed to a state of “subjunctivity,” of opened possibilities of outcome and hope (Whyte 1997, 216; see also Good 1994, 153). Similar observations can be found in the literature dealing with affliction and illness in Tanzania (Dilger 2005, 244 ff.; Langwick 2011, 155).

These authors suggest that another way of apprehending the uncertainty of severe life-threatening illnesses is the way patients approach diagnoses. Often, leaving the encounter with a healer—be it biomedical or non-biomedical—with an ambiguous diagnosis allows the afflicted to remain in a subjunctive state. The aim of such an encounter is not to obtain certainty, but a certain sense of security: the afflicted—to the best of their abilities—acted to address the causes of affliction. Because “uncertainty can only be hedged, not ruled out” (Whyte 1997, 211), for such an encounter to be deemed successful, there is no need for a clear-cut diagnosis.

This way of looking at affliction often conflicts with that of biomedical practitioners whose main concern is the objective analysis of pathological processes, frequently without consideration for patients’ experiences and interpretations. It gets, however, more complicated when it comes to mental disorders. There is no blood test, nor genetic marker for many mental illnesses. Therefore, diagnosis often entails a great deal of uncertainty and relies on the subjective conclusion of clinicians (Davies 2014).

To deal with this uncertainty, Lutindi clinicians often used the umbrella term “mental illness” when describing a patient’s condition to me and families, and, rarely, to patients themselves. Diagnosis was also subject to change during hospitalization. Evaluation interviews had a bi-weekly schedule in an institutional context of clinical rotation, which meant that a single patient was always evaluated by different clinicians. Therefore, if a diagnosis was changed from bipolar

disorder to schizophrenia (e.g. for the discharge file), this would be in line with the general label of “mental illness.” And as doctor Ngeleja, one of the younger practitioners in the hospital, explained, they were treating mental illnesses, not specific disorders. “First, you need to have restraint and listen to what the family and the patient have to say,” he once told me when I enquired about diagnosis. “But then, towards the end of the interview, you tell them the *truth* [my emphasis]: ‘this is a mental illness.’” And in time this certainty could be apprehended by patients.



Working therapy was an important part of the Lutindi rehabilitation program. The work was often carried out on a small farm annexed to the hospital. Copyright: Florin Cristea

When I asked Godlisten about the different experiences he had with hospitals and with traditional healers, he told me, “Some things from the *mganga*, they are not sure to heal. They become... *bahatisha* [hazard].”

“What does *bahatisha* mean?” I asked.

“It is some kind of luck,” Godlisten explained. “Good luck, or bad luck, it is some people’s luck. They are not sure. It makes the treatment work better or not.”

“And the doctors in the hospital?”

“They are surer of their medicine.”

For Godlisten, uncertainty was part of the treatment prescribed outside of the hospital. Although he acknowledged doctors' medical certainty, he preferred combining the different treatment traditions over following only one therapeutic path, as they responded to different symptoms.

However, occasionally patients were as skeptical about biomedical interventions as they were about other healing practices. Consider the following example of Juma, in his early fifties who, before losing his job in 2011, worked for most of his life as a clinical officer in Dar es Salaam. He listed several events that contributed to his illness. First, he was robbed in the early 1990s, and due to a heavy blow to his head during this incident, began to hear voices for the first time. A few years later, the voices returned during a bout of cerebral malaria. Next, in 2007, he got into a fight with his maternal aunt [*mama mdogo*] who allegedly bewitched him, hoping he would lose the real estate he was supposed to inherit. During the time closer to his hospitalization, the overconsumption of alcohol triggered his latest phase of hearing voices. When I asked about his experience with different treatment traditions, he told me:

The treatment you get in the hospital is comparable with the treatment you get from the traditional healers. Some traditional healers are just after your money. But some of them can do very good. It is also something I learned in the hospital. They do not have a proper treatment for this. It is similar to AIDS. They do not have a proper cure for AIDS. Also, in the case of mental problems, I don't think in the hospitals they have a permanent treatment.

In summary, I argue that, to cover for the contingencies of recovery burgeoning in an environment suffused with uncertainty, patients, families, and kin – although not always in agreement – decided for combining different treatment traditions. Furthermore, during this process they did not necessarily feel the need for a tailored diagnosis for the illness. In light of these insights, I argue that diagnostic uncertainty occurs if the following conditions are met:

First, practitioners in the hospital communicate neither the name (according to the diagnostic manual used), nor the consequences of the diagnosed mental illness to the patients and their relatives. However, they evoke certainty by using an umbrella term (“mental illness”) for a variety of symptoms that would normally be attributed to distinct diagnostic labels.

Second, patients and families usually neither challenge this broad diagnosis, if it is given at all,

or the fact that consequences of the illness are not being communicated to them. This does not happen because of obedience to clinical authority, but rather as part of the mutually shared project of maintaining uncertainty.

Third, diagnostic uncertainty needs to be made use of within a therapeutic context that includes different medical traditions (both biomedical and non-biomedical), upon which patients draw throughout their illness trajectory. As previously argued, the ability to alternate between different treatment traditions can represent a resource for coping with the uncertainties of severe chronic illnesses and can generate hope. Non-biomedical treatments in this medical context are not to be considered “alternative” or “complementary” healing practices to biomedicine but need to be ascribed similar potency. As was, for example, the case with Godlisten who believed that the medicine prescribed by the hospital targeted one set of symptoms, while those prescribed by the traditional healer were effective for another one.

Diagnostic uncertainty and moral experience

In this blog piece, I identify two consequences of diagnostic uncertainty for patients’ experience in Lutindi. First, it made the prolonged hospitalization time of around two months less bearable for patients because what was at stake and what it meant to be “good” for clinicians, did not coincide with patients’ definitions, leading to a tension that they never discussed during evaluation interviews or otherwise. Especially among urban male patients, not being able to return to their life outside of the hospital was experienced as an inconvenient break from their duties and responsibilities *as men*. Due to illness, they were either unable to start families or, because they struggled to hold down jobs while on medication or sick, they could not care for the families they had already built. Furthermore, because of the side effects caused by anti-psychotics, they could not maintain an active sexual life. What was at stake for them was the ability to return to a life in which they may be heads of households and fulfill the responsibilities they associated with “being a man.” In other words, what was important for them did not correspond to the hospital’s moral order.

Second, patients did not feel disconnected from the moral worlds outside of the hospital while hospitalized—not even if they have been struggling with schizophrenia for more than 20 years. This was the case for Henry Maalim who, up to the point of this latest hospitalization worked as a road engineer despite dealing with schizophrenia for nearly 30 years. He told me, “[My family] will look for a job for me even on the moon. But then they say, ‘Ah! But why does your illness not stop?’ Because I am sick since I was 19.” He then added, “I fear to become totally crazy.... But I learned here in church that everything will be okay.” Upon discharge, he planned to not only live a life in “God’s way,” but also to return to the traditional treatments he gave up when admitted. By adding another treatment layer, uncertainty was maintained. So was the hope that he could one day return to his full responsibilities as a father and head of household.

Definitions of living a “good life” for Lutindi patients remained anchored to the life-worlds outside of the clinic. Susan Reynolds Whyte compellingly showed that preserving uncertainty in Eastern Uganda kept people connected to their moral worlds during times of affliction (1997,

155 ff.). Similarly, I tried to argue in this text, maintaining uncertainty through diagnosis during hospitalization was what kept Lutindi patients connected to their moral words outside of the hospital.

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Author

Florin Cristea is a PhD candidate at the Institute of Social and Cultural Anthropology at Freie Universität Berlin. Combining methods and epistemologies from psychological and medical anthropology, his current research focuses on emotions and mental illness in Indonesia. Previously, he explored the clinical experience of people with a diagnosis of a mental illness in Romania and Tanzania.

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[1] According to clinicians from my fieldwork, the number of psychiatrists in Tanzania varied between 30 and 50. The last official count I identified mentions only 18 psychiatrists (Mbatia and Jenkins 2010, 1029) in a country with over 55 million citizens.

[2] As per the request of the medical administrator, I have used the actual name of the hospital. However, I have anonymized the names of the research participants, community members, and clinicians.

[3] Using the term “patient” or “outpatient” raises some ethical dilemmas, discussed in more detail, among others, by Foucault (2004, 144), Scheper-Hughes and Lovell (1986, 160-161), and Myers (2015, 10 and 81). While I am aware of the identity politics associated with these terms, I will nevertheless use them throughout this blog piece as local, emic terminology. For the same reason, I will refer to medical practitioners with the term “doctor,” although the formal university requirements were not fulfilled to hold this title.

[4] Henry Lefebvre (1991[1971]) defines “lived space” as the space of subjective experience (ibid., 33), the space of everyday life, which is “situational” and “relational” (ibid., 362-363). In other words, social relations and interaction produce space and therefore the object of interest should shift from “*things in space*, to the actual *production of space*” [original emphasis] (ibid., 37).

[5] Morality in this sense is not to be understood as a broad ethical code, but rather as local ways people come to be recognized as “good” (Kleinman 1999; Luhrmann 2001; Mattes 2012).

[6] The term “traditional” in “traditional healer” should not be understood in contrast with the term modern, as the phenomena it refers to are not defined by immutability, but by the history and culture of certain social groups (Hobsbawm and Ranger 1983, 14). My own understanding of “traditional” healing and healers stems from the definitions given by my research participants who oppose these healing practices with those of the hospital or other biomedical institutions. Therefore, I have translated the Kiswahili terms *waganga wa kienyeji* (literally local healers) and *waganga wa asili* (literally naturalist/herbalist healers) to “traditional healers” by which I

refer to non-biomedical practitioners that make use of medicinal plants in their work (for a more detailed discussion on the different terms attributed to “traditional healers” in Tanzania, see Langwick 2011, 87-88). Wa/Mganga, which I translated simply as “healer”, apart from dealing with plants also promise treatment against ailments associated with witchcraft. I maintain this distinction to guarantee the fluidity of my text. However, in common discursive practices these definitions at times overlap.