Social Sensations of Symptoms
Embodied Socialities of HIV and Trauma in Uganda
Lotte Meinert and Susan Reynolds Whyte

ABSTRACT: The interpretation of sensations and the recognition of symptoms of a sickness, as well as the movement to seek treatment, have long been recognised in medical anthropology as inherently social processes. Based on cases of HIV and trauma (PTSD) in Uganda, we show that even the first signs and sensations of sickness can be radically social. The sensing body can be a ‘social body’ – a family, a couple, a network – a unit that transcends the individual body. In this article, we focus on four aspects of the sociality of sensations and symptoms: mode of transmission, the shared experience of sensations/symptoms, differential recognition of symptoms, and the embodied sociality of treatment.

KEYWORDS: embodiment, HIV/AIDS, PTSD, sensations, sociality, symptoms, trauma, Uganda

Sensations and symptoms are socially shared, as well as individual, experiences. The sensations of one mindful body are not perceived only by that individual, but often also by immediate others. The interpretation of sensations as symptoms of a sickness is practically always a social process, as is the movement to seek treatment that often follows upon recognition of symptoms. One approach to sensations as social emphasises cultural schemas; it tends to anchor the attention primarily in individual bodies in relation to symbolic systems and ritual interventions (Hinton et al. 2008a). This approach recognises that ‘for each individual, the body is known through personal and social representations of the body, and the processes by which these representations occur must be studied across cultural and historical contexts’ (Hinton et al. 2008b: 141). We would like to take the discussion further in emphasising the importance of social interaction and recognition – not only for the conversion of sensations into symptoms but also for some sensations in themselves. Other scholars have taken steps in this direction as well. In his study of the placebo effect, Moerman (2002) suggests that social interpretations fundamentally define experiential sensation. Hay (2008) writes of how experienced sensations are transformed to cognitive interpretations to communicate them and proposes a revised sensation-to-symptom model that can be useful in understanding patient sensations as cultural and social phenomena as well as physiological ones (ibid.: 201).

Yet what if the social comes first? What if some sensations are mainly ‘sensible’ by others? It is this concern with the sociality of sensations and their recognition as symptoms needing attention that we pursue here.

The material we explore in this article comes from separate research projects in Uganda on two different conditions: HIV in central and eastern Uganda and trauma (and cen spirits) in the Acholi region of the north. These are illnesses that are often initially discovered in or by intimate others, even before symptoms are recognised by the patient. Together they allow us to describe four aspects of the sociality of sensations and symptoms: mode of transmission, the shared experience of sensations/symptoms, differential recognition of symptoms, and the embodied sociality of treatment.

Our method for generating the data was intermittent anthropological fieldwork. Most of the HIV/
AIDS material was collected between 2005 and 2007 and one case (Anna) has been followed from 1997 to the present. This involved visits and re-visits to our interlocutors’ homes for interviews and conversations. In the HIV studies, we spoke mainly and repeatedly, but not exclusively, with the patients in their homes and working places. Our interlocutors were men and women (between 30 and 50 years) from many walks of life (farmers, teachers, civil servants, soldiers, traders), probably a little better educated than the average in this age group. They were from rural Eastern Uganda as well as from Kampala, the capital. We were a group of eight researchers, speaking different local languages, so there was no need for interpreters in the interviews. We found our initial 48 interlocutors through seven different treatment sites, and then followed 23 of these people more closely over 18 months, visiting each eight times (for details about this study see Whyte 2014). In coding the material, we found that sociality was one of the predominant themes.

The trauma and cen study grew out of work we had done on the resettlement process after the Lord’s Resistance Army war (Whyte et al. 2013) and a study on reburials (Meinert and Whyte 2014). In the course of those studies, we talked with many families affected by cen spirits, and we explored NGOs and health facilities offering treatment for trauma (Whyte et al. 2015). We interviewed diviners dealing with cen, and Christian clergy who counselled victims of cen. Since August 2014 we have been more systematically adding to our understanding of these matters by interviewing 19 families who claimed to be affected by cen. We found these families through our two interpreters in Awach sub-county and did interpreted interviews in the Acholi language in their homes. Some families were visited only once, others were visited and interviewed two, three and four times. Families in this area live mainly from subsistence farming and a few had shops or did small scale trading in Awach trading centre.

As part of this study we also revisited two health facilities where trauma was treated, and had conversations with ajwaki and with a psychologist at an NGO specialising in the treatment of post-traumatic stress disorder (PTSD). The study is ongoing and is carried out in Awach sub-county and Gulu town in Gulu district.

‘Our Sickness’ – HIV

In Uganda people sometimes talk about HIV and AIDS as ‘our sickness’, an acknowledgement that it can affect everyone, not simply rich people, or city folks, or sex workers. It is also ‘ours’ in the sense that it is shared within families. Consider how Anna, an educated woman in her thirties, found out about her illness and HIV status through the symptoms and deaths of her daughter and husband.

You know at that time I did not even know my status, but then my daughter died. I took long to know what the kid was suffering from, what we were all suffering from. I did not know that the child was born HIV positive. I just saw she was growing small, and skinny, skinny. I started knowing from the child because this kid was growing so skinny, and I was asking myself why? We had money and could afford good feeding. It is the child that opened up my eyes. I was also losing weight, but I thought it was the stress from the child being always sick. […]

It was only after moving in all those hospitals, using local medicines, taking the child to the grandmother, all those local beliefs – ah – now I know that it was just the AIDS. I took her to Busia for TB treatment and they told me the child has to do an HIV test. They counselled me before they told me that... your child is positive. I got so disorganised, and I thought: It means that even me, I have it! […] My daughter was sick on and off, and we were in and out of hospitals until one day she died in my arms. […] So I decided to test myself in the main hospital and I found that yes for sure, I was also positive, and that is when I started on ARVs [antiretroviral medicine]. I had seen many people going [dying], including my own daughter and husband, so I knew I had to do something to stay in this world. […] So that is how I learned how I was [HIV positive]. When I started falling sick and getting all these different problems, diarrhoea, pain in the legs, I always thought about my daughter – was this how she felt? She used to complain that her feet were so painful, and later I understood what it meant. I could not even walk.2 (Excerpt from conversations with Anna 2003)

Anna experienced sensations of illness but she only began to interpret them as symptoms of HIV when she learned of her daughter’s diagnosis and when her husband sickened and died. Her own sensations of pain in her feet and legs, and her experience of diarrhoea, gained meaning in the light of her daughter’s sensations and symptoms.

This aspect of the sociality of sensations and symptoms follows from the fact that HIV is a contagious disease contracted primarily through intimate relations – sexual partners or mother-to-child transmission. HIV usually has a long and individually variable incubation period (from HIV infection to AIDS symptoms), which means that infected persons may not sense anything that might be taken as a symptom for
years. It is often after experiencing symptoms in children and partners that they begin to attend to their own bodies for sensations that might be symptoms. This is especially the case if a child or partner has been diagnosed. Otherwise it was often in retrospect that people interpreted the unexplained death of an intimate other as an indication that their own sensations might be symptoms of HIV.

In some cases, people seem to ignore sensations or symptoms that might lead to a diagnosis. Whether they do so consciously or not, they may be informed by others who sense signs of their illness. Saddam, a soldier, whose story is recounted elsewhere (Kajubi and Whyte 2014), told us that he did not realise he had lost weight. Yet his wife, with whom he was on bad terms because of his girlfriend Betty, announced the fact aggressively: ‘Get a mirror and look at yourself! Your ribs are sticking out. You have got AIDS from Betty.’ Another interlocutor in the same study was Jolly, whose boyfriend Boxer told her he had tested positive. She recounted that her blood ran cold. She was so frightened that she did not want to know the symptoms of HIV. ‘I never wanted to see anything about HIV and AIDS, neither adverts nor posters.’ Years later, when she had been unwell for weeks with fever and a painful swelling in her armpit, she was relieved that the clinic she attended had no means of testing for HIV. When a doctor insisted on taking blood to send for testing and bundled her into an ambulance as soon as he received the results, she still did not want to know the results. She strongly resisted the movement from sensation to symptom of a deadly disease (Twebeaze and Whyte 2014).

In our study of antiretroviral therapy in Uganda we have emphasised that:

‘Biomedicine reinforces the individual delimitation of bodies almost by definition. Testing blood, examining signs, giving medication, and monitoring outcome are focused on single bodies. But people were not preoccupied with the experience of their own bodies. In important ways they embodied sociality. People did recount their symptoms, but they did not dwell on them. They described changes in their bodies, for the better and the worse, but very often these were told in terms of what they meant for the ability to act and interact.’ (Whyte et al. 2014: 234)

Moreover, the movement from sensation to symptom to treatment was a social process to the extent that we considered sociality to be embodied in the increasing health of those well cared for and belonging to antiretroviral therapy programmes. The state of the body, and therewith its sensations, reflected the social relations in which it was embedded (ibid.: 234–35).

Despite massive, partially successful, efforts to encourage greater openness about HIV, it is still a discrediting condition that many try to deny or keep secret. Not wanting to know followed from not wanting others to know, but it was also motivated by dread of having a potentially deadly disease. Before widespread access to treatment, when testing was less common, physical changes were evidence of the disease. Because of its mode of transmission, people were attentive to changes in the bodies of immediate others, into which they read meaning for their own bodily sensations. We turn now to another condition, for which changes in affect and behaviour are evidence of sensations that could be symptoms.

The Traumas of Children

During the two-decade long war in northern Uganda, both combatants and ordinary people experienced terrible atrocities. People were injured and killed in the fighting; corpses were not treated respectfully, as Acholi convention requires. The Lord’s Resistance Army abducted approximately 20,000 children and young people; many were forced to carry out or watch brutalities. Those who survived and escaped often had problems when they returned to their families. They acted strangely and seemed withdrawn or violent. Humanitarian agencies and the meagre mental health facilities introduced the diagnostic category of PTSD. While biomedical management of PTSD was uncommon (Whyte et al. 2015), the locally known disorder called cen was often invoked to explain the sensations and symptoms of those disturbed by the legacies of violence. Cen, the bitter spirit of someone who died violently and unjustly, is thought to affect perpetrators, victims and witnesses of violence, and even their family members.

In our study of PTSD and cen in northern Uganda after the civil war (Meinert and Whyte forthcoming), it was clear that we had to talk, not only to individuals, but families, for four reasons. One was that the symptoms of trauma and cen were recognised mainly by family members. Although individuals showed that they were experiencing sensations, they often seemed not to recognise them as symptoms. Another reason for talking to families rather than only to the sick person was ethical, because in this way we could avoid stirring up unwelcome memories by asking about symptoms and possible causes. A third aspect was that PTSD and cen affect the family as a whole.
Just as HIV sensations were described in terms of their effects on interaction, so did trauma and *cen* disrupt the sociability of the family. A last reason for the focus on families was that the *treatment* of *cen*, and sometimes the cause of *cen*, was a social problem rather than an individual problem.

Sitting in her small compound in the shade of a papaya tree, Sophie is preparing cowpea leaves for lunch as she tells us about the problems with her son. She is a widow about 60 years old, a small, wrinkled, kind-looking woman. Four of her six children were abducted during the war and only one of them came back, a son, now 28 years old. He was abducted by the rebels when he was seven, and he stayed in the bush for five years. Now he has a problem. Sophie says that he did not talk much about what happened to him. He was just quiet, but sometimes he would cry and say: ‘you forced me to kill – I did not want to kill’. Sophie recalls that after he came from the bush he was okay for some years, he got a wife and they had two children. He only had a small mental problem at that time. But he was beating his wife badly for every little thing she did wrong, so finally the woman left.

They tried the traditional ritual of moyo, where the elders gather, kill a goat, and do a cleansing of the affected person. That cooled him down for some time, but the thing came back and sometimes he would move from home very early and go to the bush and sit and wait for the whole day. He would just walk silently around or sit on a chair; he would refuse food, and he lost a lot of weight. They also tried the hospital. He was given some drugs at Lacor hospital and at Awach Health Centre. It helped him for some time, but he did not want to continue to take the drugs.

Sophie thinks that what caused her son’s problems is *cen*. He mentioned that once he tried to stop a friend from beating someone. Seeing his ‘weakness’, the LRA fighters told him to do the job himself: ‘Go kill – or we will kill you!’ Then he went to kill the person. That thing, Sophie points out, can cause *cen*. That is what they think is the problem. So now the dead person is complaining: ‘You killed me for no reason. I did nothing to you!’ Sophie says she does not know what to do now, and the thing is affecting the family in a way that the son does not seem to realise or attempt to control. (Excerpt from interview with Sophie, 2015)

Sophie and her family sensed that her son was experiencing disturbing feelings, not so much because he put them into words but because of the way he acted and interacted, which caused the family great concern. Veronica’s son, also a returned abductee, terrified the family. His marriage dissolved because of his shouting and running wildly about. His mother said that he gets very angry, especially if he sees a family member talking on the phone. She shows us how she hides her phone in a small purse under her dress, because if the son sees it, he will beat her up. ‘He has a problem with phones, and we don’t know where it comes from’, says Veronica. His brother says: ‘it is very difficult to help him. If you have to convince him to go to hospital, you have to do it very slowly’ (Excerpts from interviews, 2015). In other words, whatever sensations the sons of Sophie and Veronica experienced were not kept to themselves, but expressed in withdrawal, angry outbursts and violence. The movement from sensation to socially recognised symptom to family attempts at treatment did not always proceed easily. In these cases, parents were among those who recognised that something was wrong. The person whose senses were disturbed was not able to put his feelings into words, much less cognise (know, be aware of) his sensations as symptoms of trauma or *cen* that required treatment.

**Sensible Sociality: Broader Perspectives**

Our cases of HIV and trauma from Uganda are specific in that they are about particular diseases in a Ugandan context, where health and sickness are often perceived as radically social issues. Yet, we also believe that these cases point to more general insights regarding sensations and the making and management of symptoms. The most basic issue is that the sensing and affected body can be a ‘social body’ – a family, a couple, a network – a unit that transcends the individual body.

This is not a new anthropological insight. In an overview of the nature of kinship, Sahlins (2013) argues that kinship is understood and practiced as ‘mutuality of being’ in societies all over the world. Kin live through one another; they are existentially connected even in their very bodies. Sahlins draws examples from a wide range of ethnographic literature, going right back to one of the fathers of anthropology, E. B. Tylor, who wrote in 1865: ‘among South American tribes [people] consciously believe that different persons are not necessarily separate beings, as we take them to be … there is such physical connection between father and son, that the diet of the one affects the health of the other … their very bodies are joined by a physical bond, so that what is done to the one acts directly upon the other’ (Sahlins 2013: 31–2, citing Tylor). This notion of personhood as essentially social, sustained by the sharing of bodily substances, food and mutual existence, has been es-
especially prominent in ethnographies of South Asia, where the notion of the ‘dividual’ as opposed to the ‘individual’ person was first put forward. Similarly scholars of African personhood have shown the interconnection of health and relations to kin. Symptoms may be attributed to disorder in relationships to the living and the dead – conditions that must be addressed by trying to put relationships right again. It is by reviewing relations to others that people begin to interpret symptoms and move on to attempted treatment. The ‘mutuality of being’ implies that bodily experience can be both affected and sensed by close kin.

Of those scholars who have attempted to develop a medical anthropology of sensations, Mark Nichter has been one of the most explicit on this point. He writes: ‘Somatic idioms of distress refer to the ways in which visceral responses to distress communicate angst to significant others. Somatic sensations resonate within one’s social universe whether consciously acknowledged or not. … Sensorial anthropology demands investigation of the social relations of sensorial experience recognizing that the sensorial is not just experienced individually, but “dividually”’ (Nichter 2008: 166).

This kind of mutuality is evident in the accounts we have from individuals and family members, although it plays out in different ways for the two kinds of conditions we have presented. In order to be more specific and to structure our comparison, we draw out four aspects of the sociality of sensations that may have wider resonance.

**Mode of transmission.** Some sensations and evidence of disorder are taken as symptoms of conditions that are transmitted in specific social ways. This is true for HIV, which is contagious from body to body with a long incubation time from infection to AIDS. As we saw in Anna’s case, attention to one’s own bodily sensations is sharpened when those close to one sicken and die. In societies of the Global North, the same pattern is evident when people worry about sensations and symptoms that might portend sicknesses their parents or siblings had. Ideas about heredity have been immeasurably reinforced in the era of genetic medicine; hereditary predispositions are seen as a kind of ‘contagion’ (transmission from body to body), yet different from viral and bacterial infection, not least in an extended time frame. Trauma and *cen* represent another kind of transmission, more akin to contamination than contagion in that wrongdoing spoils minds and families. Sophie looked to the social situations that linked her son to immoral violence; like pollution, the wrong to which he was exposed corrupted his person, changed his behaviour and tainted the family. Such notions of contaminating influence are also common in Europe and North America; lay people and mental health professionals relate feelings and behaviour to relations with parents, and sometimes to traumatic experiences of the parents.

**Shared experiences of sensations/symptoms.** Sensations are often conceived as individual experiences, first-order perceptions that are unique to the embodied self. It is only when they are recognised that they can be communicated as possible symptoms of a sickness. While this may be true to some extent, our material and the writings of other scholars show how the sensations of one person may be conveyed without words to others who also sense fear, anxiety and confusion. This is clearly seen in the examples of trauma and *cen*, where family members were distraught and frightened and puzzled. Even pain, famously the most private of experiences, is socialised and shared, as Livingston (2012: 119–51) has compellingly argued in her chapter on pain in a Botswana oncology ward. She writes of how relatives ‘read’ patients closely, noticing their restlessness and silences. ‘Though pain threatens to isolate an individual in his or her body, ideally (if not always in practice) every effort is made to socialize it, through active affirmation of its presence, through palliation, through laughter, through bodily contact’ (Livingston 2012: 149). In our HIV study, we heard many accounts of people sharing pain.

Reading the body, feelings and behaviour of another is a nearly universal human experience in relation to small children. Cases of children later found HIV positive, as was Anna’s daughter, illustrate a more general phenomenon. ‘When children do not yet have a vocabulary to express the sensations they feel, it is mothers who have to interpret what is troubling a child using their “common sense” as well as their own senses’ (Nichter 2008: 174). As children grow up they learn and are socialised into systems of recognition of sensations and symptoms. Although experiences of bodily sensations take place in the individual child, they are social processes in the sense that children learn, by trying out with others, which sensations are acknowledged and validated as symptoms, and responded to as sickness (Meinert 2001: 90).

**Differential re-cognition of symptoms.** Much as sensations may be shared or expressed in a way that is sensible to others, it is very common that the self who is unwell is not the first to realise that he or she has a symptom needing treatment. This was evident in the
trauma and *cen* cases, where the disturbed person was having troubling sensations, but seemed unable to interpret them as symptoms of a treatable condition. In the cases we described, mothers and grandmothers recognised what the young men could not understand. With HIV, others may perceive a symptom before its owner does, as we saw when Saddam’s resentful wife told him to take a look at himself in the mirror. A conventional distinction between symptom and sign revolves around the difference between a subjective experience and an objective indication of a disease noted by others, especially health professionals. Our point is not about subjective and objective indications of sickness. Rather we are concerned with the social processes by which others may notice something that suggests a need for treatment and communicate this to the person who may or may not have sensed anything untoward.

*The embodied sociality of treatment*. Our study of people taking antiretroviral therapy evoked stories of how people achieved and maintained treatment through the mediation of others. Through connections, by becoming clients, with support from family members and health workers, they alleviated their symptoms. As we followed them over a year and a half, we saw how these forms of sociality facilitated changes in their bodies to the extent that we thought of sociality as embodied. In our study of trauma and *cen* it was even more pronounced how access to treatment of different kinds was mediated through the social, because the patients were unable to initiate treatment themselves. It is not surprising that healthseeking and treatment are social processes. However, we should not think of these as linear movements. The mindful body requires continual monitoring by immediate others, as they try out different treatments and consider their effects. It is not simply a matter of moving from sensation to symptom to treatment. Sensing and cognising sensations as symptoms are persisting processes, as the unwelcome feelings alleviate, and then return in the same or different shapes.

**Conclusion**

Our cases of HIV and trauma from Uganda make clear that the sensing/sensed, affecting/affected and treating/treated body is often a social unity or assemblage that reaches within and beyond the individual mindful body. This is partly so because some illnesses are transmitted in intimate relations and sensed and recognised in the intimate other before they are recognised in and by the embodied self. We have seen how women come to recognise sensations in their own bodies as symptoms of HIV only after experiencing the sickness and death of children and husbands.

Sensations – first-order perceptions – and signs in an individual body only become symptoms when they are cognised by the self or others, and re-cognised as indications of illness. Often these are not straightforward social processes where all parties agree on and recognise symptoms at the same time and take action in unity. They are more likely to be negotiated and sometimes contested processes. Families with members who suffer from trauma in northern Uganda often have to negotiate carefully with the affected person about self-recognition of symptoms in order for treatment to be possible. Moreover, raising money to pay for treatment is almost always a social and shared responsibility in families and thus often troublesome.

In Uganda HIV is often talked about as ‘our problem’ – not only in a positive sense – and trauma is experienced as something that affects the whole family – not just the damaged individual. Treatment is perceived and practiced as a social achievement, because the way to connect to and maintain treatment is always through the mediation of others. The success or failure of treatment is an embodied form of sociality. It may serve as a public health reminder that illness processes right from sensations to symptoms, to diagnostics, treatment and prevention are radically social processes and need to be addressed as such.

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Notes

1. The empirical data presented here is drawn from several research projects. Our HIV cases were part of a collaborative study of AIDS medicines carried out under the TORCH project (see Whyte 2014). One of the HIV cases was followed as independent fieldwork (see Meinert 2014). Our study of trauma (and cen) is part of the EPICENTER project (http://epicenter.au.dk) and the project on ‘Post-conflict mobility: challenges and potentials for primary health care in northern Uganda’. Ethical clearance for these projects was obtained through Gulu University and Uganda National Council for Science and Technology.

2. For more of Anna’s story see Meinert (2014).

References


