

Measuring PTSD: Circumstances, the Language of PTSD, and Prolonged States of Disorder in Northern Uganda

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Abstract

This article examines how trauma, a vague expression encompassing a wide array of debilitating circumstances, is conceptualised and measured as post-traumatic stress disorder (PTSD) in northern Uganda. More specifically, it examines the misrepresentations produced by the measurement of PTSD and asks what injuries are inflicted upon people's everyday lives by these misrepresentations. The aim is to draw on Wittgenstein's insistence that it is necessary to grasp the circumstances under which concepts and instruments are used in order to understand the misrepresentations that occur, in this case, around the use of instruments to measure PTSD. The paper discusses two cases of ordinary hospital days, where everyday research routines make disorder visible. It argues that these exceptional circumstances, with traumatising consequences on patients, provide critical insights into the inner workings of the apparatus of mental health and how this apparatus is intricately interwoven with the ordinary conditions of everyday life.

In this paper I examine how trauma, a vague expression encompassing a wide array of debilitating circumstances, is conceptualised and measured as post-traumatic stress disorder (PTSD) in northern Uganda.⁵ More specifically, I attend to the apparatus of mental health research in northern Uganda, which deploys standardised instruments to assess what part of the population is at risk of PTSD.

After the end of the war in northern Uganda in 2006, studies on mental health revealed a high rate of PTSD in this region. These rates are of course statistical estimates, though they may not be unexpected after two decades of war, displacement, and encampment. Nonetheless, commentators like Morton Jerven question the accuracy of statistics in African countries arguing that donor assistance is often misled by 'poor numbers' (Jerven 2013). In this paper I suggest that a lack of accuracy is not the only problem haunting the measuring of PTSD in northern Uganda. On the contrary, the desire for accurate numbers is a driver for the development of more reliable techniques to test the validity of measuring instruments in mental health research. Moreover, these instruments underwrite the rapid proliferation of measurement systems in various fields of global governance (Merry 2011, Rottenburg *et al.* 2015). One of the reasons for

⁵ I am very grateful for helpful and inspiring comments by Andrea Behrends, Siri Lamoureaux, Rene Umlauf and the anonymous reviewer.

this trend is that standardised measurement systems simplify complex problems for decision-making processes. In the case of PTSD, the instruments consist of a set of questions inquiring into the multiplicity of risk factors, which are weighed and calculated to assess PTSD cases and to compare PTSD rates across different places and populations. In this respect, numbers are not misleading, but, according to Wendy Espeland, simplifications are the very reason ‘why we value indicators so much and why we often feel they *misrepresent* us’ (Espeland 2015: 77, my emphasis).

In this paper, I examine the misrepresentations produced by the measurement of PTSD and ask what injuries are inflicted upon people’s everyday lives by these misrepresentations. My aim is to draw on Ludwig Wittgenstein’s insistence that it is necessary to grasp the circumstances under which concepts are used in order to examine the misrepresentations that occur, in this case, around the use of instruments to measure PTSD (Wittgenstein 1953). This examination of circumstances is inspired by Veena Das’s suggestion that reading Wittgenstein prompts us to ‘descend into the ordinary’ to understand everyday violence (Das 2007; see also Cavell 2007). Following Das’s argument (2007), I will examine the circumstances under which the language of PTSD is evoked and translated to endorse an understanding of violence grounded in the ordinariness of everyday life. As I maintain here, these circumstances are overlooked and misrepresented by mental health research concerned with measuring determinants, stressors, or conditions of PTSD.

My discussion of the ordinariness of everyday violence will elaborate a critical analysis of measuring PTSD and the emphasis it is given in current mental health research. This emphasis is seen in a range of scientific practices to standardise measures for PTSD and subject these measures to scientific testing. These tests essentially seek to demonstrate that questions about the exposure to traumatic events are correctly translated into the language spoken by respondents—in the case of this paper, Luo. As I argue in this paper, such practices of translating and testing instruments, foundational for the idea of transcultural psychiatry, show far more about the workings of the apparatus of mental health than the actual measuring of PTSD.⁶ Here, I draw on Wittgenstein who rejected the belief that the meaning of concepts and more generally representations of a certain reality could be tested by giving a correct translation (Wittgenstein 2003). Such tests do not fail due to the incommensurability of different worldviews. Rather, testing the translation of PTSD verifies only that part of the reality that constitutes the condition of possibility of mental health research. What is translated in the development of standardised measures is a distinct language of PTSD to legitimate mental health interventions in the name of humanitarian assistance and development (Pigg 1997, Rottenburg 2002).

More specifically, my aim in this paper is to argue that the apparatus of mental health is intricately interwoven with the ordinary conditions of everyday life. Understanding everyday life in post-conflict northern Uganda has to take a large number of projects into account, which Susan Reynolds Whyte, Lotte Meinert and their colleagues elaborate as the projectification of health care in Uganda (Whyte *et al.* 2013, Meinert & Whyte 2014). In this projectification, mental health research is conducted and more generally claims to scientific objectivity are raised under the same circumstances of existential insecurities characteristic for everyday life in post-war northern Uganda. It is this form of existential insecurity that is circumscribed by the vagueness of the term trauma and its wide use in northern Uganda, in contrast to the medical term PTSD.

⁶ See Jörg Potthast (2012) and Rene Umlauf (2015) for social scientific accounts of testing. According to Umlauf, testing constitutes a distinctive epistemic practice of contemporary global health interventions.

The projectification of health care is perhaps even more pronounced in northern Uganda than in the rest of the country; images of child soldiers, abductions, and a horrifying Lord's Resistance Army attracted a broad range of humanitarian relief organisations and research projects evoking the language of PTSD. Erica Caple James argues that the language of PTSD authorises claims to restoration in what she terms the political economy of trauma (James 2004, James 2010). The language of PTSD, however, fails to provide a detailed and nuanced account of the messy politics of war and displacement and its interpretation in the broader region, which is necessary to understand the trauma of war in northern Uganda (Allen & Vlassenroot 2010).

In this paper I address the everyday conditions under which trauma and mental health research prolong states of disorder after the official end of the war. My discussion of the language of PTSD is not denying the devastating experience of war, violence, and trauma. Rather, the effects of the projectification of health care, as I maintain in this paper, bring the experience of trauma into sharper relief. In what follows, I will first provide a brief description of the measurement of PTSD and the broader apparatus of mental health research in the context of northern Uganda. I will then discuss two cases. The first case is about a single person, whom I will here call Grace.⁷ I discuss a conversation with her to illuminate what I mean by the circumstances underlying the experience of trauma in the post-war context of northern Uganda. More importantly, the events making her life unliveable show the limits of mental health in addressing traumatising conditions of everyday life. This first case will be juxtaposed with a second case concerned with the instruments used to measure PTSD. The second case describes how practices of testing these instruments unintentionally produce traumatising experiences. Both cases are based on field research, which I conducted in 2011 and 2012 in northern Uganda. I present these two cases in the form of an extended case study connecting a series of events that prolong states of disorder (Burawoy 1998). An important reason for looking at the circumstances is to endorse that an ethnographic understanding of description *shows* rather than *tells* how concepts of PTSD or how technologies of measuring PTSD are used by experts and health professionals.⁸ The ethnographic task of showing cases of traumatisation is not a simple one and in the absence of a satisfying solution, I stress the circumstantial dimensions of my own field research, which I will make explicit throughout the paper.

Trauma and the Language of PTSD

According to Chris Dolan, the term trauma had been widely in use during the peak of armed conflict in northern Uganda (Dolan 2009). Dolan notes that during his research on the so-called IDP camps between 1998 and 2002, it 'was very common for people to say "we are all traumatised"' (Dolan 2009: 6). Trauma was, according to Dolan, even a currency, which he initially dismissed as being a politically charged expression. Similarly, James suggests that the production of trauma narratives in the case of Haiti belongs to a political economy of trauma emerging out of terror economies intersecting with a 'compassion economy of trauma' (James 2010: 107). In fact, the war between the Lord's Resistance Army and the Ugandan government was exacerbated by everyday life in the IDP camps. As Dolan clarifies, the notion of trauma

⁷ All names in this paper are pseudonyms.

⁸ See Duerr (1985) and Rabinow (2008) on what Wittgenstein termed 'übersichtliche Darstellung' (in English: 'clear representation') in his discussion of Frazer's *The Golden Bough* (Wittgenstein 1967).

reflected the debilitating living conditions in the IDP camps, which instead of protecting people, constituted a form of ‘social torture’ (Dolan 2009).

The medical term PTSD, understood as a mental disorder, has been an integral element of the apparatus of mental health in northern Uganda emerging immediately after the end of the war in 2006. One of the first accounts of PTSD was provided by Roberts et al. (2008a, 2008b, 2009) in a series of articles based on their research in two IDP camps in 2006. These studies provided one of the first assessments of PTSD rates in northern Uganda. One of the articles describes a qualitative investigation in which the authors conducted semi-structured interviews on the ‘social determinants of health’. Asked how life in the camp affected health, respondents are quoted saying that: ‘mental disorders can come as a result of too many thoughts about poverty [life in IDP camps]. What you used to do and things you used to see and have are not there. If you think deeply about them, you can develop mental illness’ (Roberts *et al.* 2009: 5).

Luo-speaking respondents describing PTSD as a ‘mental disorder’ and a ‘mental illness’ is surprising, in particular, as the authors state that the interviews were conducted in Luo by one of the co-authors fluent in English and Luo. To what extent the interviewees used these terms is not stated, while the analysis omits a closer examination how the medical term PTSD relates to the term *cen* widely used to account for ‘madness’, which can be literally translated as the spirits of the “resentful dead” (Meinert & Whyte [forthcoming]; see also Finnström 2008). This is not to say that the authors failed to match terms like mental disorder (presumably more neutral than madness and more general than PTSD) to local concepts like *cen*. Rather words, experiences, and scientific knowledge are to an indefinite extent fused in everyday language in the post-war environment of northern Uganda (Dolan 2007; see also James 2010). What interests me most is to examine the specific circumstances under which concepts are used in everyday life, which essentially includes concepts and models derived from the scientific language evoked by mental health research.

A parallel quantitative study to measure the rate of PTSD among IDPs conducted by the same authors confirmed the mass traumatisation of the population. According to the study, 52.2% of the population evinced the symptoms of PTSD giving strong evidence for the debilitating conditions found in IDP camps (Roberts *et al.* 2008a). Quantitative studies to measure the rate of PTSD highlight that the strength of scientific rigour lies in standardising the translation of both questions and answers. The instruments used to measure PTSD consist of a set of questions on the exposure to traumatic events, which are based on the translation of the Harvard Trauma Questionnaire into various languages (Mollica *et al.* 1992). There is an Indochinese version of the Harvard Trauma Questionnaire (Mollica *et al.* 1992) and a French version for French-speaking sub-Saharan Africa (de Fouchier *et al.* 2012), which all passed the validation test. The Luo version too was found to be a valid translation by the above-mentioned group of authors (Roberts *et al.* 2008b).

I mention these exemplary studies to bring to the fore that terms like trauma and practices of measuring PTSD have been early on an integral part of everyday experiences of war and humanitarian assistance in northern Uganda. The circulation of these measurement instruments suggests that PTSD constitutes a model that travels from one post-conflict setting to another (Behrends, Park & Rottenburg 2014). Understanding PTSD as a travelling model stresses that translation is more than a linguistic operation. In the case of PTSD, a set of instruments, models, and ideas gets translated into a particular setting stabilising a specific conceptualisation of trauma as PTSD.

In the case of northern Uganda, PTSD is translated under circumstances that are less than ideal and are moreover ignored by the apparatus of mental health promoting ideas of evidence-based medicine. As Dolan writes, the experience of violence is far more ambiguous than the language of scientific objectivity deployed in trauma projects. The boundaries between mental health research and its research objects, between perpetrators and victims, between conflict and humanitarian assistance lack the moral clarity expected of it. To quote a longer passage:

*If your whole world has become the torture chamber, then determining a clear beginning becomes hard (...). Forcible displacement prior to an act of individual torture does not just render the victim more susceptible to PTSD symptoms after such an act, it is a part of the torture process itself. Just as the beginning is hard to pinpoint, so is the end. What people experience and the symptoms they exhibit can barely be described as post-traumatic, as for most people **there is no end to the circumstances**, which caused the trauma. Whereas the aid workers in war zones are sent on R and R (Rest and Recuperation), there is no such respite for the population at large. From this point of view to use the term post-traumatic stress to describe what is happening inside the war zone can itself be seen as part of a structure of denial, or at least a refusal to acknowledge that there is no 'normal' or pre-traumatic situation to revert to. (Dolan 2009: 14, my emphasis)*

The passage highlights that the circumstances of ordinary life in IDP camps under which people experienced trauma did not have a clear beginning or end. The prolonged state of disorder in the aftermath of war escapes the language of mental health, which divides everyday life into a discrete number of conditions and events to be measured as PTSD. Moreover, mental health research focused on specific conditions implicitly presumes that its instruments are deployed under 'normal circumstances'—necessary for ensuring that methods can be replicated and that findings are not biased. As I show in the following ethnographic part of this paper, the implicit assumption that knowledge about disorder is produced under normal circumstances is conflated with the ordinary circumstances of everyday life in Uganda shaped by the large number of donor projects in the country (Whyte *et al.* 2013, Meinert & Whyte 2014).

Not plain PTSD

In July 2011, I visited several hospitals in northern Uganda to conduct interviews with patients on HIV treatment in the course of my research on the logistics of antiretroviral medicines in various Ugandan districts. The interviews were conducted with the help of Joyce Akol who had worked as an interpreter for several research projects in northern Uganda. Our visits to HIV care and treatment programs always followed the same procedure. We made contact with the officer in charge of the hospital the day before our visit and asked for permission to conduct interviews. At the hospital we would first introduce the project and describe the research questions before interviewing patients.

One of these visits took place at a hospital close to the border of South Sudan. After introducing our research question on the availability of HIV treatment, the clinical officer in charge provided us with a room to conduct interviews. He immediately directed a group of women to us. We decided to conduct a focus group discussion instead of individual interviews that would delay them from returning home. In 2011, HIV treatment had been rapidly rolled out in the whole country and, in spite of serious stock-outs in the previous years, the supply of antiretrovirals had stabilised and our interviews focused mostly on patients' past experiences of stock-outs. Before we could pose our questions on the availability of antiretroviral medicines, we noticed that one of the participants of the focus group, whom I call Grace, looked restless. Grace was incessantly rubbing her arms as if she felt uncomfortable. We stopped the focus group discussion immediately and Joyce asked Grace in Luo if she was not feeling well. Grace started to talk non-stop to Joyce for more than one and a half hours. During this conversation, she would turn her head towards the wall to hide her tears. Joyce just listened and at times interrupted her to ask a question to understand better or to translate for me.

Grace stayed in Palaro, between Gulu town and the hospital where we were seated. A soldier from the Ugandan army had taken her as a wife at the age of fourteen while she was living in the IDP camp. She produced five sons and one daughter. During her fifth pregnancy, she was diagnosed with HIV and started to take Septrin, which is prescribed as prophylactic treatment before patients start antiretrovirals. She told her husband to go for a test, too. He refused and started to beat her and steal her Septrin. She would try to hide it, but he would always find the pills. At one time she even stopped coming for her refills, because it seemed to be useless. Yet, these drugs were meant to save her life, as she told us. The birth of her last son was a nightmare. She almost died on the way to the health centre. Her husband had refused to take her to the hospital and she had to crawl the last miles until she could pay somebody 500 Uganda shillings, about 0.14 US dollars, to drive her to the hospital. Then her husband left her and her children. During this period, she heard that he was staying in Gulu with another woman and taking antiretrovirals from Gulu.

Then two years ago he suddenly returned and demanded sex. She first refused. Then she became pregnant again and gave birth to a daughter, also HIV positive. Her husband brought his other wife to settle on the land she was using. So Grace left and moved to her parents' place. But her brothers told her she should stay with her husband. They would come during the night and steal from her garden. She would quarrel with her brothers although they had left already and she was alone in her hut. Then she would quarrel with herself. She could hardly sleep these days. Her eldest son, twelve, dropped school to dig in the garden and feed the younger ones. She constantly worried about her children. She thought of moving to Gulu to do casual labour. But it was not easy to move to Gulu with six children. She thought of suicide, but who would take care of her children? Joyce and I could not help other than by asking her if she was receiving any support to 'get some rest', which she denied having. When she wanted to leave and return home quickly, we gave her some money to pay for transport.

Grace was not receiving psychosocial support when we met her. Her case may corroborate the need to expand the coverage of mental health services in northern Uganda, embark on sensitisation campaigns, and screen the population more systematically. However, I mention Grace not to support or object to mental health care, but to draw attention to the circumstances under which people get screened, diagnosed and treated for certain conditions, or are neglected. Furthermore distinguishing these circumstances from other statistical terms like

determinants, conditions, or stressors provides insights into the workings of the mental health apparatus.

Her story differs remarkably from the findings presented by Roberts and others above in their study on health determinants in northern Uganda. Yet her experiences were not unique among the women we interviewed later on. Their experiences of everyday violence contrasted with the narrower definition of war-related violence underlying common understandings of PTSD. There was no single clear-cut traumatic event resulting from armed conflict. Rather, Grace described her worries, sleepless nights, and hopelessness as a series of events prolonging the state of disorder in her life.

There is a controversy in mental health research concerning what counts as causes of PTSD. The anthropologist Allan Young in his work on PTSD among Vietnam veterans describes how psychiatrists' assessments of PTSD were centred around practices of distinguishing between false or complicated cases, on the one hand, and cases dubbed as 'easy diagnosis' readily meeting the case definition of PTSD, on the other (Young 1995: 149). Similarly, health professionals in northern Uganda describe those latter cases as 'plain PTSD', which suggests that in practice the diagnosis of PTSD is often more difficult. A case of plain PTSD evinces a clear causal relationship between the experience of war-related violence and a state of mental disorder, which contrasts with the many circumstances manifesting as a state of disorder exemplified by Grace. It was not one single traumatic event that emerged in the conversation with Grace, but rather an array of traumatising events. There was neither a temporal nor a causal order but many ruptures and breaks in her narration of violence. Her experience of the IDP camp, the abusive husband, the HIV infection, and the fighting over land⁹ had accumulated over the years reaching a point where her life had become unliveable.

The psychiatrists Miller and Rasmussen argue that 'stressful social and material conditions' should be included in the assessment of PTSD and other mental disorders (Miller & Rasmussen 2010). The authors define these conditions as 'daily stressors', comprising poverty, the loss of livelihood, and the unbearable living conditions in IDP camps—a definition that seems to explain Grace's state of disorder. The psychiatrist Frank Neuner, who conducted extensive mental health research with former abductees in northern Uganda, questions the practical implications of addressing all these daily stressors (Neuner 2010). According to Neuner, mental health research is far too influenced by the latest donor fashions instead of focusing on what professional psychiatrists can realistically achieve (Neuner 2010: 1343).

Grace's experiences were extreme but not unique in post-conflict northern Uganda. These experiences highlight the necessity of bringing the circumstances prolonging states of disorder into fuller view. Medical anthropological contributions to an understanding of the current expansion of medical research in African countries point out that these circumstances accrue from weak public health infrastructures lacking proper diagnostic technologies and medicines (Feierman 2011, Livingston 2012). Moreover, these patchy health infrastructures essentially include newer global health interventions embracing particular diseases, providing resources for these diseases, and establishing whole infrastructures of specialised care, while other diseases and public health care are ignored (Pfeiffer & Chapman 2010, Whyte *et al.* 2013; 2014; Meinert & Whyte 2014, Prince & Marsland 2014, Geissler 2015).

⁹ None of these experiences, except her forced marriage during the era of IDP camps, are directly related to war. Yet there might be correlations; for instance land conflicts in northern Uganda have been on the rise after people returned to their homes (Obika & Mogensen 2013, Lenhart 2013).

The experiences underlying Grace's state of disorder intersect with the projectification of health care, which Whyte and Meinert elaborate on concerning the expansion of HIV treatment (Meinert & Whyte 2014). The HIV treatment programme that Grace attended was funded by an international donor agency offering HIV services twice a week. In contrast, the mental health day was a late introduction at the same hospital and was held on another day of the week. The number of PTSD cases recorded in the register books was much lower than expected. The majority of 'mental health' cases were epilepsy, followed by bipolar disorder, a pattern found across most hospitals in northern Uganda. In contrast to the antiretroviral therapy programme of the hospital, the mental health clinic did not receive any 'NGO support' as the psychiatric nurse told us. Anti-depressants were regularly out of stock. The mental health clinic lacked reference books. Fuel to transport severe cases to Gulu Hospital or visit families of the mentally ill was lacking. Yet these HIV treatment and mental health service were provided by the same hospital. Good mental health services were instead provided outside the public health system by various NGOs specialised in psychotherapy, but were limited in their capacity.

According to the nurse and other mental health practitioners in northern Uganda, a major reason for the low attendance at mental health clinics is that the signs and symptoms of PTSD first lead people to traditional healers and churches, which may be effective under certain circumstances. However Grace's case points toward a quite mundane reason, namely, that attending the hospital takes time and costs money for transport. Such costs are undertaken in life threatening conditions such as shown by the birth of Grace's youngest child. This does not mean that trauma and PTSD are harmless conditions or that mental health services are completely absent in northern Uganda. Rather it is to suggest that these conditions are bound up with the production of order and disorder by donor assistance.

Testing the Translation of PTSD

In this section I elaborate on the circumstances shaped by the projectification of health care by examining the measurement of PTSD. After my research on HIV treatment, where I had met Grace, I participated in a collaborative study on chronic treatment in northern Uganda the following year in 2012 (Whyte *et al.* 2015). This study examined the visibility of PTSD, depression, diabetes and hypertension among out-patients in northern Uganda. Within this collaborative study we counted 25 non-governmental organisations providing mental health services and conducting applied mental health research. Some organisations were specialised in the provision of psychotherapy for PTSD patients like the Alderman Clinic at Gulu Hospital funded by a philanthropic organisation from the US. Other organisations were providing psychosocial support. Still other organisations, for example the Association of Volunteers in International Services, were addressing PTSD within their projects on economic recovery and sustainable livelihood. Finally, a variety of mental health research projects conducted surveys on PTSD on a regular basis.

Most of these projects based their intervention and surveys on instruments to measure and assess PTSD (see Figure 1 below). As mentioned above, a widely used blueprint is the Harvard Trauma Questionnaire based on the Diagnostic and Statistical Manual of Mental Disorders, which is often combined with the John Hopkins Symptom Checklist-25 to measure depression. In practice, there is a great diversity of tools. Other organisations prefer questionnaires based on the ICD10 classification system of the World Health Organisation. Furthermore, trauma projects pursue different research interests such that tools are adjusted to

the research objectives or require the collection of additional demographic data. The tools themselves are relatively cheap compared to other diagnostic equipment. The questionnaires are basically photocopies, which are easily reproduced for screening large populations.¹⁰ Time for administering these questionnaires is the most important cost. Moreover, the administration of these questionnaires requires a clinical professional. These instruments allow for the screening of large populations, but do not replace a diagnosis by a medical doctor. An interviewed person is considered to be at high risk of PTSD when the score of the answers passes a predefined threshold. That person has to be referred to a hospital for a proper diagnosis.

Figure 1: Questionnaires

These two questionnaires are examples of the instruments used to collect data during the collaborative research on chronic medication. The questionnaires were also translated into Luo. Responses on each question item were weighed and allowed the calculation of a final score.

Project: _____				
Participant code: _____		Interviewer: _____		
Date: _____		Place of Interview: _____		
The Harvard Trauma Questionnaire—Parts I and IV				
Instructions				
<i>We would like to ask you about your past history and present symptoms. This information will be used to help us provide you with better medical care. However, you may find some questions upsetting. If so, please feel free not to answer. This will certainly not affect our treatment. Your response will be kept confidential.</i>				
Part 1: Traumatic Events				
<i>Please indicate, by answering ‘yes’ and ‘no’ whether you have ever experienced (E), witnessed (W), or heard stories (H) about any of the following events</i>				
Trauma event experienced	Experience d	Witnessed	Heard stories	Never
1. Lack of food or water				
2. Lack of housing or shelter				
3. Unnatural death of family member or friend				
4. Murder of family member or friend				
5. Being close to, but escaping, death				

¹⁰ The Harvard Trauma Center charges a fee of 130 US dollars on its website for the complete manual, which will be distributed in the form of a CD. However, beyond this fee, I believe, there are no other cost aspects involved as in the case of health assessments by other diagnostic technologies like Rapid Diagnostic Tests for malaria, microscopes and so on.

6. Ill health without medical care				
7. Witnessing the murder of stranger(s)				
8. Tortured or beaten				
9. Forced separation from family				
10. Being abducted or kidnapped				
11. Made to accept ideas against your will				
12. Serious injury				
13. Forced isolation from other people				
14. Being in a war fighting situation				
15. Imprisonment against your will				
16. Rape or sexual abuse				

Part IV: Trauma Symptoms

Instructions

The following are symptoms that people sometimes have after experiencing hurtful events in their lives. Read them to the person being interviewed and circle the number that best describes how the respondent has been feeling in the past week using the following scale: 1 = not at all, 2 = a little bit, 3 = quite a bit, 4 = extremely.

Trauma symptom	not at all	a little bit	quite a bit	extremely
Recurrent thoughts or memories of the most hurtful or terrifying events	1	2	3	4
Feeling as though the event is happening again	1	2	3	4
Recurrent nightmares	1	2	3	4
Sudden emotional or physical reactions when reminded of the most hurtful or traumatic events	1	2	3	4
Feeling detached or withdrawn from people	1	2	3	4
Unable to feel emotions	1	2	3	4
Avoiding doing things or going to places that remind you of the traumatic or hurtful events	1	2	3	4
Inability to remember parts of the most traumatic events	1	2	3	4
Less interest in daily activities	1	2	3	4
Feeling as if you don't have a future	1	2	3	4

Avoiding thoughts or feelings associated with the traumatic or hurtful events	1	2	3	4
Feeling jumpy, easily startled	1	2	3	4
Difficulty concentrating	1	2	3	4
Trouble sleeping	1	2	3	4
Feeling on guard	1	2	3	4
Feeling irritable or having outbursts of anger	1	2	3	4

The validation of these instruments plays a critical role since a false assessment of PTSD has far-ranging implications for the respondents. An instrument is considered to be scientifically valid if questions on the exposure to traumatic events yield the same responses in any language. In the case of northern Uganda, questions translated from English into Luo need to yield the same response as in any other possible language. The validation of tools is a test of whether questions on the exposure to trauma were translated correctly. This test occurs in two steps. First, the questions are translated into Luo. Secondly, the items are ‘back-translated’ from Luo into English to test the correctness of the translation. The first translation requires a bilingual expert. The back-translation requires someone who is not familiar with the original questionnaire. In most cases this will be an informant from the target population. Finally, the ‘concordance’ of these two translations is evaluated and measured. Each of these steps can be refined to eliminate subjective interpretations and thereby increase the objectivity of PTSD measurement.

During our collaborative research project on chronic treatment, we—Morris Ojara and George Odong, two fourth-year medical students, and myself—attended a mental health clinic day at a health centre. The day of our visit happened to be very busy. The AIDS Support Organisation, known as TASO, which is one of the largest providers of HIV care and treatment in Uganda, was running an outreach on that day and a large group of patients had gathered around a tent in the compound. Construction work was going on at the back of the health centre building.

In addition, a non-governmental organisation specialised in psychotherapy had come for the mental health day to assist the health staff. Moreover, this NGO had brought a researcher from Kampala whom I will call Jeanette, to run focus group discussions in order to validate the measurement tools. Finally, our team was looking at the records on PTSD, depression, hypertension, and diabetes.

During our stay at this health centre, I talked to Jeanette, who explained that she had come to see if her organisation was ‘getting the numbers we want to reach in these communities’. When I asked her about the low number of cases of PTSD opposed to the large number of cases of epilepsy, Jeanette immediately explained:

That is why we measure. If we realise that the communities are mostly affected with epilepsy, then we would not completely pull out, but we would reduce the number of outreaches. We need to get the effect we want. The outreaches help us to get to know that patients with PTSD or depression are traumatised. We gauge that health centre. Like for instance in Arua District and at the first

outreach that had been suggested at Adjumani. But most of the patients there have epilepsy. So we are now changing the direction to the refugee settlements. That is where most of our patients are traumatised.

Jeanette had come to the health centre to validate the instruments used to measure PTSD. These instruments had been translated into Luo with the aim that patients would at some point administer the tools themselves. Since she did not speak Luo, as she told me, her colleagues from the local NGO were running the validation of the tools. Luo questions were translated into English and then back into Luo by the participants of two focus group discussions.

After a couple of consultations, the social worker, whom I will here call Dennis, began with the validation of the translation by randomly inviting twenty patients for the focus group discussions. During one of the discussions, the newborn of a young mother was continuously coughing and had difficulty breathing. Jeanette interrupted the focus group discussion and asked if the young mother with her coughing son should not see a doctor. But no health worker was present, as the NGO was running its mental health day and Dennis was a social worker. Dennis looked at her and searched for the patient records. The mother had come with her newborn a week ago. Her three-week-old son had been coughing and had refused breastfeeding. She had presented the complaints to the clinical officer who diagnosed a respiratory tract infection. The clinical officer gave her a prescription of erythromycin syrup and paracetamol. As the young mother told us, the medicine had been out of stock at the health centre and she had to buy them at a local drug shop. Over the last days, her son was only 'suckling a bit', and there was no improvement. So she returned with her son and her younger sister to see the clinical officer, who was not present on this day; instead she ended up in a focus group discussion. It happened that Kenneth Okello from our research team had conducted his internship as a medical student at this same health centre a few months ago. He immediately admitted the mother and the son, prescribed antibiotics, and wrote detailed instructions for the nurses. Jeanette felt extremely sorry and gave the sister of the young mother 20,000 Uganda shillings for transport.

After the focus group discussions were over, another female participant remained seated. She did not move and was sweating. She suddenly started to cry. She was pregnant and had been bleeding. Dennis immediately called Kenneth again, who came and made a preliminary examination and admitted the women to the in-patient ward. The bleeding had started the day before with clots and lower abdominal pains. No vomiting. She felt dizzy. She had sat throughout the whole focus group discussion without asking for help. It was her sixth month of pregnancy and it may have been a miscarriage.

For the validation of the instruments any random patient could have been selected. Yet two of the patients had come to the hospital for acute problems and needed immediate care. Kenneth Okello's swift intervention raises the question about the many contingencies and uncertainties that characterise an ordinary health facility day. And more importantly, the measuring of PTSD is influenced by the frequent lack of staff and the large number of projects at this health unit.

It is important not to mistake these circumstances for determinants or stressors causing PTSD. Instead these experiences form the existential ground of everyday life. Mental health research wrongly presents itself as independent of such circumstances in its use of words, numbers, and technologies. Under 'normal circumstances' the focus group discussions could have been routine. However, the exceptional circumstances described above are the rule at Ugandan health facilities. Social workers like Dennis fill in for the notorious lack of health

professionals at government hospitals. The contingency of health service delivery experienced during an ordinary day also includes Kenneth's improvising care in the absence of an ultrasound machine and other diagnostic equipment to confirm his initial diagnosis.

Prolonged Disorder

I presented two cases on trauma in this paper to exemplify the circumstances under which people experience trauma, which essentially includes the broader humanitarian apparatus. In both cases, the circumstances make a life unliveable and moreover reproduce the trauma that characterises the prolonged state of disorder in the region. It is not my aim in this paper to ask if the term PTSD is applicable in the context of northern Uganda. Nor do I want to question the need for mental health services in northern Uganda. Instead, I wish to draw attention to the fusion of words and languages in the everyday experience of violence, which opens a range of questions about the translation of trauma into the scientific language of PTSD.

Both cases also describe ordinary but exceptional hospital days, where everyday routines make disorder visible. Following Wittgenstein, I examined how instruments used to measure PTSD are validated by looking at the circumstances under which the concept of PTSD is used. In contrast to Wittgenstein's philosophical argument, this paper focused on less ideal conditions characterising the health system in northern Uganda. I juxtaposed the two cases assuming that they show us more about the inner workings of the apparatus of mental health. The circumstances making life for Grace unliveable contrast with the imagination of plain PTSD cases and the methods used to assess these cases which all presume a temporal and causal order between the exposure to violence and the development of mental disorders. By contrast the prolonged state of disorder presented by Grace was unordered and more importantly included the living conditions created by the projectification of health care. In the second case, I suggested that the validation of instruments for measuring PTSD tells us more about the scientific language of PTSD than the actual measuring itself; and more importantly how states of disorder are prolonged by the projectification of health care.

Circumstances just seem to happen and viewed from any particular situation none of them could have been anticipated. The exceptionality characterising an ordinary health facility day gives an idea as to how states of disorder are prolonged, how the simplicity conveyed by the language of PTSD creates misrepresentations, and how these misrepresentations inflict physical injuries on people's lives. They remind us of Walter Benjamin's famous thesis on the concept of history: 'the tradition of the oppressed teaches us that the "state of emergency" in which we live is not the exception but the rule' (Benjamin 1986: 257). In paraphrasing this thesis we may need to attain a conception of science 'that is in keeping with this insight' (Benjamin 1986: 257). That is, a conception of science that acknowledges the exceptional and often unexpected circumstances under which people seek care and provide help.

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