

Understanding Narrative Transformations of Ebola in Negotiations of Epidemic Risk

N. W. Paul, M. Banerjee

Abstract—Discussing the nexus between global health policy and local practices, this article addresses the recent Ebola outbreak as a role model for narrative co-constructions of epidemic risk. We will demonstrate in how far a theory-driven and methodologically rooted analysis of narrativity can help to improve mechanisms of prevention and intervention whenever epidemic risk needs to be addressed locally in order to contribute to global health. Analyzing the narrative transformation of Ebola, we will also address issues of transcultural problem-solving and of normative questions at stake. In this regard, we seek to contribute to a better understanding of a key question of global health and justice as well as to the underlying ethical questions. By highlighting and analyzing the functions of narratives, this paper provides a translational approach to refine our practices by which we address epidemic risk, be it on the national, the transnational or the global scale

Keywords—Ebola, Epidemic Risk, Medical Ethics, Medical Humanities.

I. INTRODUCTION: EPIDEMIC RISK BEYOND DATA

ONLY very recently, the health care situation in those regions plagued by Ebola is returning to routine [1]. However, the question what can and must be learned from the recent Ebola outbreak, especially with regard to the response of national agencies and international organizations such as the World Health Organization (WHO), has been asked long before the return to normality [2]. In the news section of the February 2015 issue of the Bulletin of the World Health Organization, medical anthropologist Cheik Niang argued in an interview entitled “The Human Factor” that taking the human factor into account is essential in fighting epidemics and/or pandemics such as Ebola. While we fully agree with this diagnosis, we suggest that for an analysis of the human factor from a translational point of view and aiming at policy changes leading to an adjustment of the practices involved when it comes to fighting epidemics, it is essential to look at narratives in a more systematic and theoretically nuanced way. “For the community, it seems that data have more value than human life” [3], is both, a bold and challenging statement urging us to reassess our probabilistic notions of evidence and employ current scientific approaches to narratives in order to

Prof. Dr. N. W. Paul is director of the Institute for History, Philosophy and Ethics of Medicine at the University Medical Center of the Johannes Gutenberg University Mainz, Germany (phone: +49 6131 17-9545; fax: +49 6131 17-9479; e-mail: institut.gte@uni-mainz.de).

Prof. Dr. M. Banerjee is chair of American studies at the Department of English and Linguistics and director of the Center for Native and Indigenous Studies at the Johannes Gutenberg University Mainz, Germany (phone: +49 6131 39-22711; fax: +49 6131 39-22480; e-mail: mita.banerjee@uni-mainz.de).

come up with enriched notions of the co-construction of epidemic risk beyond data. From our point of view, it is crucial to look at the narrative transformations of Ebola. Here, the identification of narrative shifts of epidemic risk from a locally confined public health problem to a global health threat is crucial. From a policy-making perspective, this means to appreciate the difference between global health and local practices as it has been championed by health organizations and NGOs throughout the last decades and to translate them into culturally sensitive practices safeguarding our notions of deliberative democracy [4]. We have to acknowledge that knowledge and political will is at hand, the practices employed to address Ebola, however, were obviously not sufficiently targeted. From an ethical perspective, this means not only to appreciate the lives affected by epidemics but to move from information and data to the underlying meanings and lived experiences calling for an adjustment of health communication and interventional measures to actually meet the existential needs of affected individuals and to safeguard their autonomy and dignity by integrating their readings of reality into our understanding of risk [5], [6]. In this paper we provide a methodological approach to the narrative co-construction of epidemic risk. In the light of the Ebola outbreak, the way in which the international community and WHO dealt with former epidemics may provide insights into specific blind spots that prevented actors and institutions from unfolding their full potential to tackle epidemics as threats to both, communities and individuals, finally leading to the current debate about the lessons that must be learned from recent missteps. We will approach the issues at stake in to major steps. First, we will explore processes of the narrative co-construction of epidemic risk with a specific focus on the analysis of narratives. We will argue that narratives provide an important contextualization that will help us avoid scenarios in which risk control is driven by institutional and economic interest – often brought about by non-human actors [7] – and thus stop short of addressing underlying social, cultural and human needs. Second, we will provide a provisional toolbox on how to access narratives and on the methodological approaches needed in order not to get lost in multiplicities of notions, meanings and readings. In our final paragraph we will offer suggestions on how to translate these analytical approaches into practices of policy making.

II. UNDERSTANDING THE NARRATIVE CO-CONSTRUCTION OF EPIDEMIC RISK

In order to understand the narrative transformation of Ebola into a risk to global health, it is important to note that such

narratives of contagion and their cultural turns do not originate in a void. Rather, they follow certain trajectories and genealogies, and respond to and take up previous threats of global health risk. In this sense, each new narrative of contagion carries with it traces of older narratives; each new outbreak of a particular epidemic will trigger previous scenarios and health threats, which had been conjured up by previous epidemics. Thus, particular cultural imaginaries are so ingrained in our mental repertoire of ethnic communities and disease outbreaks that they are “triggered” by every new instance of fear of a new epidemic. Thus, the first step towards understanding the recent dramatization of Ebola is to understand its narrative chronology and choreography in order not to underestimate the power of narrative to shape our reactions to epidemics. This includes news reports as well as assessments and suggestions presented by global health institutions. How seriously these suggestions are taken and the ways in which they may be implemented, in fact, may depend to a large extent on the way in which they are conveyed in narrative.

In order to unveil the narrativization of Ebola, accessing the metaphorical content of “outbreak narratives” [8] as such is essential. Narratives of the outbreak of a particular epidemic as a risk to global health have certain features in common. In order to understand the narrative chronology of the Ebola outbreak, it is important to identify these features. As a next step, we must separate the features common to the (generic) outbreak narrative as such from the specific features that can be found in narratives of Ebola in particular. At first, however, it is important to note that narratives of contagion work on two separate but interrelated planes. First, they dramatize the fear of contagion, which is often connected to particular actors who are identified as the “carriers” of the disease. Secondly and even more importantly, however, the degree of dramatization and scandalization will depend on the extent to which these carriers can be contained. As long as those who are identified as potential carriers of risk are seen as being contained geographically, the risk of contagion seems calculable. Once the carriers are seen as being connected to global routes of trade and economic exchange, however, there is a sense in which contagion threatens to become global. According to Pricilla Wald, “[accounts of epidemics] put the vocabulary of disease outbreaks into circulation and introduced the concept of ‘emerging infections’. [...] Collectively, they drew out what was implicit in all of these accounts: a fascination not just with the novelty and danger of the microbes but also with the changing social formations of a shrinking world. [...] Disease emergence dramatizes the dilemma that inspires the most basic of human narratives: the necessity and danger of human contact.” [8, p. 2].

Epidemiology and pandemic risk are evidently inseparable from the human bodies targeted as the carriers and “spreaders” of the epidemic. The drama of the epidemic plays itself out through the “dramatis personae of an unfolding tragedy” [8, p. 3]. What seems specific to Ebola, however, is that the first cases of Ebola seemed to be confined to particular locales in Africa, such as Guinea, Sierra Leone and Liberia. These

narratives, in turn, drew implicitly on older, culturally and ethically unacceptable narratives of Africa as the “dark continent” or the “forgotten continent”, metaphors which in recent years have been updated in epidemiological terms. Especially the scandalized HIV/AIDS epidemic with its global hotspot south of Sahara created a notion of futility in dealing with global health issues under African circumstances.

It is crucial to note here that the first media reports about Ebola particularly involved human interest stories, which are, by nature, deeply rooted in local cultures. In the case of Ebola a featured video of the New York Times [9] followed a local ambulance driver fighting an epidemic, which could not be contained. The paramedic Gordon Kamara is shown in his efforts to help people in Monrovia, fighting Ebola seemingly on his own. Even as the video evokes sympathy, it simultaneously treats Ebola as an infection, which is far removed from the Western world, and which can hence be viewed at a distance, albeit a highly sympathetic one.

By stressing the localness of the outbreak by presenting individual stories, the threat of global risk is kept away from the audience. This assurance by Western news media, that Ebola was confined to Africa as a continent, was reflected in early news reports. When the camera shows a dead body lying in the middle of the road, surrounded by an angry crowd, this is not only a symbol of otherness, it is also a message to the Western audience that circumstances as they would most likely not appear in most industrialized countries are contagious in their own right.

Kamara [voiceover]: “We are an ambulance team. The job is very very hard. They said that the body had been there for a long time, so that’s why they got angry. [The camera shows the body being loaded on an open pick-up truck]. The entire city is covered with bodies. There’s nothing we can do. My name is Gordon Kamara. I’m an ambulance nurse. From March up until now, I’ve been fighting these Ebola cases. Our job is to save the people” [9]. The scene is followed by the following caption: “In a city of around 1.5 million roughly 15 ambulance teams fight the outbreak street by street.” [9].

The narrative of risk was hence kept at bay through the assurance, by health officials, that the threat to human health was not global. If, as Wald [8] suggests, the drama and the scandalization of epidemic outbreaks increase to the extent that the carriers of contagion travel on global economic routes, news coverage of Ebola dispelled this threat. Rather, these narratives of Ebola in Guinea, Sierra Leone and Liberia were characterized precisely by the absence of mobility. In fact, the tragedy inherent in the unfolding of Ebola on the African continent was all the bleaker because authorities and health workers seemed to be left largely to their own devices. This is evident in the news report on Gordon Kamara fighting Ebola “street by street.” The fact that the outbreak of Ebola was hence “local” in a number of ways, at once assured Western audiences that the carriers would not travel; Ebola was narratively at a remove from the Western world.

III. UNDERSTANDING THE NARRATIVE BIAS OF RISK

But how did the threat of contagion spread as the health crisis wore on? Crucially, the narrative of Ebola took a turn, which to some extent differs from previous epidemics such as SARS or the swine flu. In these previous cases, the carriers were often depicted as businessmen or tourists, connecting global routes of leisure and economy to global contagion. In case of the outbreak narrative of Ebola, on the other hand, the carriers who would threaten to spread the disease were physicians and health care workers. As Wald [8] has noted, one characteristic of the outbreak narrative is the blurring of lines between “victims” and “agents of infection.” In each and every narrative of outbreak, those who suffer from a disease become carriers of risk, if unwittingly so. In the case of Ebola, this blurring of lines between victims and agents was all the more pronounced since the “carriers” of contagion had been infected when trying to provide medical assistance to local communities. As Wald goes on to suggest: “Their unwitting role in the spread of the new virus turned these unfortunate sufferers into stock characters of a familiar tale. The epidemiological precedent of an ‘index case’, responsible for subsequent outbreaks, quickly transformed these figures from victims to agents – and embodiments – of the spreading infection.” [8], page 3.

Narratives about the coming of Ebola to Western countries through routes of a globalized medical system, then, were characterized, above all, by a sense of shock and surprise. Despite the fact that Africa had been falsely depicted as largely being outside global routes of trade and commerce, it had turned out that the disease could not be confined to spaces outside of globalization [10]. The sense of shock was thus connected to an increase in the drama of the outbreak narrative. Ebola had now indeed reached global proportions. This recognition, in turn, immediately affected narratives of medical assurance and certainty. Another New York Times video on October 15, 2014, suggested as much, showing how responses by the Centers for Disease Control changed in only a short course of time: Through the voiceover, two official interviews with CDC director Thomas Frieden are juxtaposed in order to show how the certainty of the CDC that the Ebola outbreak was under control gave way to admissions of uncertainty. Frieden: “We know how to stop outbreaks of Ebola.”

Frieden: “I wish we had put a team like this on the ground the day the patient [...] the first patient [...] was diagnosed.

The crisis was exacerbated by multiple misunderstandings and struggles over responsibility. As the news video goes on to note, in the case of an Ebola case in Dallas, the CDC left it up to local hospitals to deal with Ebola. “In Dallas, the approach leaving the hospital in charge led to multiple apparent protocol breakdowns. The hospital nurses recently claim there were confusing and frequently changing policies and protocols” [11]. As Dr. Daniel Varga of Texas Health Resources subsequently admitted: “We’re a hospital. We may have done some things different with the benefits of what we know today.” As the CDC subsequently noted, the case in Dallas led to a shift in policy: “Now in response to these

concerns, Director Frieden has announced a more direct role of the CDC when working with hospitals. In any future cases an Ebola response team will now directly monitor the local medical staff’s use of protective gear.” This change in policy, which is meant to assure the public that cases such as the one in Dallas will not be repeated, is also mirrored in Thomas Frieden’s announcement: “We will put a team on the ground within hours” [11].

For the public, in turn, the admission of medical uncertainty at once raised the stakes of dramatization in the outbreak narrative. For the medical community, dealing with Ebola became a reality even in the most remote hospital settings, since everyone and every institution was working to fill the void in knowledge and practices [12]-[20]. As these instances show, there is a close connection between the communication of medical certainty, risk and the outbreak narrative [21]. What is hence at stake is also the way in which medical authorities deal with and communicate mistakes: As Hannawa et al. observe: “The discourse of medical errors has [generated] considerable research interest in recent years. [...] Recent research has moved beyond the issue of financial responsibility and its consequences to the relational and medical outcomes of effective and ineffective disclosures. Further, as patient safety has become a primary focus of the World Health Organization (WHO), hospitals are becoming increasingly interested in comparative assessments of their safety cultures [...]” [22].

In order to make sense of this complex turn in narratives of certainty, it is important to consider some of the key parameters of medical discourse. Medical discourse can be understood as a future-oriented theory and narrative of probability [23]. In the case of Ebola, the reconstruction of certainty hinged especially on non-human actors, in this case risk control through isolation wards. After the narrative turn of events in which not only medical personnel had been infected but, when subsequently being treated at American and European hospitals, had in turn spread the infection, there was a need for reassurance of the public.

The reconstruction of certainty hinged on elaborating the technological working of isolation wards as the containing of risk. In fact, highly elaborate descriptions of the technical mechanism of isolation units through disinfection and respiratory protective devices were meant to counter admissions such as the one quoted above that containing the risk of contagion had not been as facile as had at first been assumed. The materiality of the isolation units was hence crucial to bringing back the narrative of contagion from one of contingency and incalculable risk to at least a provisional certainty.

Among such non-human actors needed to re-establish certainty in terms of keeping future infections at bay were also economies of immunization, by and large driven by the notion that the development of pharmaceutical agents to fight Ebola would not generate economic benefits for companies which would justify the step from bench to bedside, from the laboratory to routine application, a step which is usually a highly regulated and tremendously costly one. Thus, even

though Ebola was a known infection, the biomedical toolbox for the treatment of the disease was more or less empty. As a consequence, credibility and trust had to be created and established by national and international agencies rather than by medical practice. Once the first cases of Ebola appeared and seemed to be spreading in Africa, the responsibilities of the public health services, the WHO, the Centers of Disease Control (US) and national agencies such as the Robert-Koch-Institute (Germany) and the Institute Pasteur (France) had to be discussed.

IV. HOW TO NEGOTIATE CULTURAL PRACTICES WITH EPIDEMIC RISK

In the dramatization of risk, cultural practices were especially important. Here, narratives of “unsafe” medical practices in Africa, which were seen as strongly lagging behind Western standards of hygiene, proliferated: stories of bodies which were left to lie openly in the streets for days, thus multiplying the risk of future infections. The above-mentioned news report on Gordon Kamara shows bodies being loaded on open pick-up trucks and equipment being cleaned in the river each morning, with the use of plain soap and with the ambulance nurse wearing no protective gear whatsoever. As Gordon Kamara notes, “In the morning, we start very fresh. This is going to be a busy day. The calls just keep coming. The calls just keep coming. There are patients all over. I tell them, ‘Don’t be afraid.’ They feel fear. I see it in their eyes. I’m tired of seeing people getting sick” [9]. While such depictions were shocking, they also served a further function for Western audiences: To the extent that medical infrastructures in Africa were “primitive” and unsafe, the danger of infection for Western countries seemed to be minimal, even in the unlikely case that one carrier of contagion should appear in the West. To the extent that news coverage focused on the insufficiency of health care systems in many African countries, then, these narratives at once served to reassure Western audiences of such news coverage that there was no impending danger for the West.

Underlying such narratives is the assumption that countries striving for a full integration into the global community and into the global markets bear a specific responsibility for the sanitation of their territories. This, news coverage of the Ebola outbreak in African states seemed to imply, was not the case on the African continent. According to Wald, “the juxtapositions supply the connections, plotting the routes of the disease from [local sites] which suggests a lack of cleanliness and propriety to the airports and cities of the global village” [8], page 5. Even if in her analysis, Wald is specifically concerned with the SARS outbreak, her account also sheds light on the dramaturgy of the Ebola epidemic.

What is at stake here is an understanding of the global village as a simultaneity of two mutually exclusive time zones, one modern and one primitive, as Wald puts it in her critique of this dichotomy. The threat of the epidemic, for her, lies in the mixing of these very time zones. It is here that Wald’s above described analysis uncannily anticipates the ways in which the SARS epidemic spreading from China to the West

prefigured the Ebola crisis: “The ‘primitive farms’ of Guangzhou [a province in China where SARS was said to have originated], like the ‘primordial’ spaces of African rainforests, temporalize the threat of emerging infections, proclaiming the danger of putting the past in (geographical) proximity to the present” [8], page 7.

In news reports about the uncontrollable spread of Ebola in African countries, depictions of “African rainforests” gave way to images of African villages; both representations hinged, however, on the portrayal of “African” local sites as spaces of uncleanness and contagion. As these considerations show, news on an epidemic such as Ebola blurs a variety of discourses: politics, and science, aspects of virology, public health, emergency plans, studies on vaccines, social and cultural practices, pride and prejudice.

As we write this paper, the rate of infection for Ebola seems to be under control, but the crisis caused by it may be far from contained. The arrival of epidemics has always been much more a threat than a challenge to cultures striving to cope with the contingencies of human existence especially in the light of health-related global inequalities and the ethical challenges that come with it. In this regard, the mismanagement of a pandemic event in modern cultures is a scandal of institutional failure, an irritating cultural experience of the loss of control and an indicator for a missing link between our values, our practices and the resulting outcomes. Thus, negotiating the sources of epidemic risk becomes a necessary reaction of national and international organizations seemingly vested with the tools to control pandemic risk to protect their institutional integrity, to limit their burden of responsibility to realistic dimensions.

At this point, however, we may well have arrived at an impasse, which involves the interface between epidemiology and cultural practice. We have implied above that news reports about Ebola in Africa unjustifiably stressed the “backwardness” of cultural and medical conditions in these countries. At the same time, it can be argued that from the perspective of epidemiology, a certain extent of scandalization of “unsafe” cultural practices is necessary in order to prevent further infection. The aim of the epidemiologist, it must be noted, is less the cultural scapegoating of persons or communities than the prevention of further infections. In order to do so, the epidemiologist must generate not only medical but also cultural data. Wald notes,

“from precedents and standardization a recognizable story begins to surface. Epidemiologists look for patterns. For Timmreck, the job of epidemiologists is to characterize ‘the distribution of health status, diseases, or other health problems in terms of age, sex, race, geography, religion, education, occupation, behaviors, time, place, person, etc.’. The scale of their investigation is the group, or population, rather than the individual, and they tell a story about that group in the language of disease and health. [...] In their investigations epidemiologists rely on and reproduce assumptions about what constitutes a group or population, about the definition of pathology and well-being, and about the connections between disease and ‘the lifestyle and behaviors of different groups.’”

[8], page 19. Thus notions of dramatizations and scandalization may leave us with a double bind: Even as we have to understand scandalization as a function of creating awareness and of living up to global health responsibility on the one hand, we must also be aware of the ways in which it may obfuscate our view of actual needs for and scopes of situated action. What is at stake is a move from an extemporaneous mode of dealing with an outbreak, characterized by decision-making in a hybrid forum of interest, institutions and individuals to an evidentiary mode, framed by knowledge including local, situated knowledge about affected individuals and their readings of the situation. Looking at narratives like the ones now present at the websites of WHO or patient narratives [24] is only a first step towards the integration of situated knowledge in an evidentiary mode of prevention and intervention. We fully agree with Jennifer Prah Ruger who is calling for a theoretical foundation enabling us to overcome inequalities and injustice for the sake of equal health opportunities. The concept of provincial globalism Prah Ruger suggested recently in the light of Ebola [25] needs to be taken seriously and should be evaluated for both, its explanatory reach and its practicability so we do not miss a chance to actually overcome the global health divide.

V.CONCLUSION

With what conclusions does a discussion of Ebola and the negotiation of epidemic risk leave us in the attempt to bridge potential gaps between medicine and cultural analyses? Crucially, it may leave us with an insight into the profound interconnectedness between “science” and “society”, between medical diagnosis and cultural assumptions. Secondly, through Ebola as a case in point, we may want to reconsider the idea of biomedical science as a global phenomenon.

The global scope of biomedical science, we have argued in this paper, must be carefully negotiated against the situated absorption and local transformation of biomedical knowledge as well as against ethical and moral standards of integrative particularism or – as Prah Ruger puts it – provincial globalism [26]. Finally, it must be noted that medicine, science and public health are cultures with their own rituals, and may hence converge much more than they differ with such practices to which we would grant such cultural constructedness much more readily. Both medicine and the humanities construct their objects. Thus, as we have tried to suggest in this publication, it would ultimately be unproductive not to take into account the ways in which a specific object is constructed, even if this link may sometimes lead to uneasy confusions and (temporary) impasses in logic. We explained how the focus on the narrative transformation of Ebola is a good venture point for an interdisciplinary understanding of medicine and cultural practices. It is this understanding and the search for a transformation of the prevention of and intervention in epidemics that we have sought to contribute in writing this paper. Now, after Ebola left us with the need of re-assessing our practices and re-defining our positions, we have to say that we are facing a new moral challenge in the field of global health and justice [27].

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Norbert W. Paul, Univ.Prof. Dr.rer.med., M.A. is Professor of History, Philosophy and Ethics of Medicine at the Johannes Gutenberg University Medical Center, Mainz, Germany, and Director of the Institute. He is also head of clinical ethics at the Johannes Gutenberg University Medical Center. His academic career includes positions at the Heinrich-Hein-University Duesseldorf, Germany, the Stanford University Program in Genomics, Ethics, and Society as well as a visiting professorship at the Stanford Program in History and Philosophy of Science, Stanford, CA, USA . He served as member of the scientific board of the Max-Delbrueck-Center for Molecular Medicine at Berlin-Buch, Berlin, Germany.

He is member of a number of scientific societies and Member of the Academy of Sciences and Literature, Germany. Since 2014 he is speaker of the DFG Research Training Program "Life Sciences – Life Writing" together with Prof. Mita Banerjee.