

## **Victim or Advocate? Conceptualising Biocitizenship in Recipients of Medical Humanitarian Intervention During South Africa's HIV/AIDS Epidemic**

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### **Introduction**

Biological citizenship, or 'biocitizenship', describes forms of belonging, claims to rights, and access to resources made on the basis of biomedical conceptions of the body, such as genetic status or disease state.<sup>1</sup> These biological constructs form an integral aspect of one's identity for the individual, or group of individuals in question, around which social relations are organised. Humanitarian intervention denotes the philanthropic allocation of resources, legitimised by a supposed apolitical morality. In the medical humanitarian setting, transnational actors, such as Médecins Sans Frontières (MSF), often take on the legitimising role. The most widely accepted definition of medical humanitarianism is that suggested by Abramowitz and Panter-Brick: 'the field of biomedical, public health, and epidemiologic initiatives undertaken to save lives and alleviate suffering in the conditions of crises born of conflict, neglect or disaster'.<sup>2</sup> The power relationship between the humanitarian actor and the recipient of humanitarian intervention is asymmetrical; the power associated with clinical intervention is, to an extent, exerted by the legitimising body and submitted to by the intended recipient.

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<sup>1</sup> Jessica Mulligan, 'Biological Citizenship' in *Oxford Bibliographies Online*, online edn, (Oxford, Oxford University Press, 2017), Available from <<http://www.oxfordbibliographies.com/view/document/obo-9780199766567/obo-9780199766567-0164.xml>>

<sup>2</sup> Sharon Abramowitz, Catherine Panter-Brick, *Medical Humanitarianism: Ethnographies of Practice*, (Pennsylvania: University of Pennsylvania Press, 2015) p. 1

Francois Debrix argues that the 'humanitarian sanctuaries' that MSF creates in order to carry out necessary intervention, denote the recipients of humanitarian aid as 'victims' lacking in individual agency.<sup>3</sup> Similarly, Peter Redfield remarks that by virtue of working in situations of crisis, medical humanitarian bodies can only maintain the lives of those they seek to help at a stage of 'bare life'— 'forms of naked existence without any of the benefits of social being'.<sup>4</sup> This suggests that the established view of humanitarian actors has been reconcilable with the concept of sovereign power, albeit for philanthropic causes; the recipient of humanitarian aid submits to a legitimising body in order guarantee order and security in the form of medical intervention.

However, MSF is increasingly focused on the long-term management and prevention of chronic health conditions. Given the rapid development of biomedical interventions to treat chronic disease states, medical humanitarian intervention is becoming increasingly focused on projects that require long-term compliance to treatment regimes. The relationship between the humanitarian agency and the recipient in this case is more consistent with Foucault's account of biopower, an analysis that aims to account for the myriad of power dynamics that exist between individuals, families and communities. It is the harnessing of power within these relationships, Foucault argues, that induces knowledge, pleasure and discourse and upon which the sovereign state relies.

As a transnational actor who does not aim to supersede more permanent political power structures, MSF must act to understand and influence the discourse of biopower within the communities in which they operate, in order to successfully

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<sup>3</sup> Francois Debrix, 'Deterritorialised territories, borderless borders: the new geography of international medical assistance' *Third World Quarterly* 19 (1998), 827-846 (p. 829)

<sup>4</sup> Peter Redfield, 'Doctors, Borders and Life in Crisis', *Cultural Anthropology*, 20(2005), 328-361 (p. 340)

manage long-term health outcomes. This includes the establishment and maintenance of antiretroviral therapy (ART) programmes to combat the HIV/AIDS epidemic in South Africa since 2001. The success of such a long-term intervention remains reliant on the active engagement of HIV-positive individuals to understand and accept a biological conception of their identity and actively collectivise around this shared identity into 'communities' of individuals that take responsibility for their own health and advocate responsible health behaviours. In turn, the biopower of communities can work to influence the discourse of the sovereign power of the state.

This essay seeks to demonstrate that medical humanitarian actors can facilitate biological citizenship as an empowering illness identity that offers an alternate label to that of the disempowered victim. The origins of biocitizenship will first be outlined through Foucault's concept of biopower. This essay will then present the respective arguments of Debrix and Redfield which suggest that the illness identity afforded to recipients of humanitarian aid is inherently disempowering. Finally, it will utilise the case study of MSF's involvement in the AIDS epidemic in South Africa to demonstrate that biological citizenship can offer an alternate illness identity to that of the disempowered victim.

### **Biopower and Biocitizenship**

Foucault's account of biopower defines a transformational shift away from the traditional top-down model of power, 'where the bearer of power dictates what those *not* in power may *not* do'.<sup>5</sup> For example, the power of a sovereign over their subjects stems from the position of the ruler to endanger the lives of the population over

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<sup>5</sup> Vernon Cisney, Nicolae Morar, *Biopower, Foucault and Beyond*, (Chicago: University of Chicago Press, 2015) p. 1

which they preside; the power to *let* live or *make* die.<sup>6</sup> Foucault refuted the notion that the power relations that have shaped human society are contained solely within established authoritarian structures. In attempting to define the power relations that influence the lives of an individual, Foucault coined the term biopower to encompass the 'explosion of numerous and diverse techniques for achieving the subjugation of bodies and control of populations'.<sup>7</sup> By this definition, power constitutes individuals who, within their networks, can submit to and exert influence in different contexts. This situates power internally as opposed to externally; the emphasis being placed on bodies and their capabilities. This new model of power emphasises the expansion and protection of life rather than its subjugation and deduction. Biopower operates around two poles: disciplinary power and the biopolitics of the population.

The emergence of disciplinary power arose in the 17<sup>th</sup> century and described the transformational shift in the perception of the human body as a machine complete with functions, utilities and predispositions to weakness. Disciplinary power encompassed the way in which these qualities could be optimised into efficient systems of control. The latter pole, that of the biopolitics of the population, applied elements of disciplinary power to the collective population. The second half of the 18<sup>th</sup> century saw the rise of epidemiological disciplines which resulted in the gathering of information such as birth rates, mortality rates and poverty statistics. This contributed to the perception of the nation as a biological entity 'that could be strengthened by attention to the individual and collective bodies of those who constituted it'.<sup>8</sup> Political power began to expand to encompass a concern for biological life. Consequently, biological health status became increasingly linked to

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<sup>6</sup> Ibid, p. 2

<sup>7</sup> Michel Foucault, *The History of Sexuality, Vol. 1: An Introduction*, (New York: Vintage Books, 1990), p. 140

<sup>8</sup> Nikolas Rose, *The Politics of Life Itself: Biomedicine, Power and Subjectivity in the Twenty-First Century*, (Oxford: Princeton University Press, 2007), p. 138

notions of citizenship. As Youde suggests, 'a person's health status had transformed itself from an indicator of biological well-being to one that influenced our status within the polity'.<sup>9</sup>

The increasing globalisation of public health surveillance over the latter half of the 19<sup>th</sup> century has also led to the development of biocitizenship at an international level. This includes the recognition that disease in one state may affect all states, either through epidemics and population displacement or through developed countries incurring the costs associated with disease relief efforts. The increased attention of the international community to HIV/AIDS is exemplified in the emergence of UNAIDS (1996) and the Global Fund to Fight AIDS, Tuberculosis and Malaria (2002); health is increasingly an international concern. The efforts of the international community to aid marginalised populations exist as a contributory factor towards the creation of what Didier Fassin terms 'modern humanitarianism'.<sup>10</sup> Fassin details the convergence of various factors that have contributed to the establishment of the modern humanitarian movement, including the globalised transmission of events that have come to constitute 'humanitarian crises', the creation of humanitarian organisations (including MSF) to serve populations excluded on the basis of health status amongst other factors, and the growth of initiatives designed to aid marginalised populations at national and international levels.<sup>11</sup>

It is against this backdrop that medical humanitarian organisations such as MSF emerged, to serve populations marginalised from their own nation states based on their biological health status. Due to the global increase in biomedical technologies and biological governance that has accompanied the management of

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<sup>9</sup> Jeremy Youde, *Biopolitical Surveillance and Public Health in International Politics*, (Basingstoke: Palgrave Macmillan, 2010), p. 9

<sup>10</sup> Didier Fassin, *Humanitarian Reason: A Moral History of Present Times*, (California: University of California Press, 2011) p. 5

<sup>11</sup> Fassin, *Humanitarian Reason*, p. 5

chronic disease states, it is no longer sufficient for medical humanitarian actors to categorise those they treat under the disempowering label of 'victim'. Instead, organisations must empower local communities with the knowledge to understand and participate in the formation of their biological identities, so that they can demand rights and access to resources to address their biological needs. MSF's establishment of its ARV treatment programme in South Africa demonstrates the potential of medical humanitarian organisations to facilitate empowering illness identities through the concept of biocitizenship.

### **Médecins Sans Frontières: HIV/AIDS in South Africa**

MSF was founded in 1971 by a group of French physicians and journalists in response to the devastating effects of the Nigerian civil war of 1967-1970. Its object was to form a new humanitarian organisation; one which aimed not only to provide medical assistance in crisis situations, but to establish an independent voice with which to condemn atrocities that inflicted human suffering. The core values of MSF are set out in its founding Charter, which advocates the principles of respect for medical ethics, independence, impartiality and neutrality, bearing witness to human suffering, and raising awareness and accountability for its activities.

The early period of MSF's history focused solely on emergency response; missions were 'largely symbolic in impact [...] and entirely temporary in duration'.<sup>12</sup> When HIV/AIDS emerged as a problem in sub-Saharan Africa in the 1980s, MSF was not impervious to the 'exceptionalism' that the epidemic elicited; the notion that HIV was so exceptional in comparison to other communicable diseases that it could

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<sup>12</sup> Redfield, p. 333

not be treated the same way.<sup>13</sup> MSF's response to acute situations of crisis readily enabled it to counter the transmissible aspects of the epidemic, 'but its conception of humanitarian medicine remained rigid, and aspects of prevention and public health, and therefore of access to care more generally, were not yet integrated into it'.<sup>14</sup>

The 1990s was characterised by a renewed media interest in epidemics, in particular HIV/AIDS.<sup>15</sup> An internal MSF document regarding the AIDS epidemic in sub-Saharan Africa stated that in the year 2000, 'No war, genocide, earthquake, flood or other epidemic has had an equally devastating impact on a nation'.<sup>16</sup> In the same year, it was estimated that 40% of all adult deaths in South Africa were due to AIDS.<sup>17</sup> It was in this context that Dr Eric Goemaere of MSF visited South Africa in March 1999 with a view to establishing the development of an HIV/AIDS ARV programme.

Goemaere's initial exploratory mission was met with resistance. On a national level, the South African government refused to acknowledge the magnitude of the AIDS epidemic and adopted a 'denialist' stance. This view was fronted by President Thabo Mbeki, Minister of Health Tshabalala-Msimang and the African National Congress Party (ANC). In response to the Medical Research Council's report in 2001 which claimed that AIDS had become the 'single biggest cause of death' in South Africa, Mbeki and his supporters retaliated with an attack on 'mainstream' AIDS science.<sup>18</sup> AIDS was promoted as the construct of an 'omnipotent apparatus [including the media, medical establishment and drug companies] that desired to

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<sup>13</sup> Renee Fox, *Doctors Without Borders: Humanitarian Quests, Impossible Dreams of Médecins Sans Frontières*, (Baltimore: John Hopkins University Press, 2014) p. 122

<sup>14</sup> Alex Parisel cited by Fox, p. 122

<sup>15</sup> Redfield, p. 333

<sup>16</sup> Document cited by Fox, p. 124.

<sup>17</sup> Quarriasha Karim, Salim Karim, 'The evolving HIV epidemic in South Africa', *International Journal of Epidemiology*, 31(2002), 37-40 (p. 39)

<sup>18</sup> Report cited by Pat Sidley, 'HIV/AIDS responsible for 25% of deaths in South Africa' *BMJ*, 323(2001), p. 89

frame AIDS as a 'black disease'.<sup>19</sup> At a local level, numerous cultural obstacles prevented the implementation of AIDS prevention programmes, including: the blaming of AIDS on witchcraft, AIDS as a mechanism for controlling black population growth and the belief that sex with virgins could cure AIDS.<sup>20</sup>

In January 1999 the Department of the Provincial Government of the Western Cape had introduced a Prevention of Mother/Child Transmission of HIV/AIDS programme in Khayletisha, the most socioeconomically deprived township in Cape Town. Of an estimated population of 350,000-400,000 individuals, at least 40,000 adults were HIV-positive.<sup>21</sup> However, patients in these programmes were not initiated on ART, in line with the government's refusal to accept that AIDS was caused by HIV.

One month into the exploratory trip Dr Eric Goemaere met Zackie Achmat, the founder of the social activist Treatment Action Campaign group (TAC). The aim of TAC was to provide all users of South Africa's public healthcare system with access to effective AIDS treatment (including ARVs), to raise awareness of HIV/AIDS and to combat the associated stigma. Throughout TAC's campaign efforts, Achmat himself refused to take ARVs for his own HIV-positive status until they were made available on the public healthcare system. In doing so, his very existence came to embody the way in which biological autonomy had come to be entwined with political governance. It was not until early 2000 that MSF was permitted to start HIV/AIDS treatment programmes at three community healthcare sites in Khayletisha and it was May 2001 before he first patient was initiated on ART.

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<sup>19</sup> Steven Robins, *From Revolution to Rights in South Africa: Social Movements, NGO and Popular Politics After Apartheid*, (Boydell and Brewer: London, 2008) p. 108

<sup>20</sup> Robins, p 104

<sup>21</sup> Fox, p. 127

It is at the interface between the individual patient-citizen and non-governmental organisation (NGO) social movement activism—observed in the MSF/TAC alliance in South Africa—that complex experiences of identity and citizenship emerge. Inclusion in educational treatment programmes can enable transformational shifts in patient autonomy by increasing the accessibility of biomedical discourse. In certain cases this can lead to the production of ‘the kinds of responsabilised citizens that public health professionals believe are required for safe and effective AIDS treatments to take place’.<sup>22</sup> At an individual level, those enrolled in MSF’s ARV programmes must learn to accept and reconcile their biological identities. MSF’s educational programmes facilitated this through education campaigns which aimed to construct a new understanding of the body as a biological entity receptive to biomedical intervention. The collectivising aspect stems from the biosocial groupings that form around a shared biological conception of identity. The latter aspect is exemplified by the MSF/TAC activism campaigns. These biosocial collectivities have contributed to a form of biocitizenship that is both individualising and collectivising.<sup>23</sup>

### **Humanitarian Action: the creation of ‘victims’**

Francois Debrix and Peter Redfield argue that recipients of medical humanitarian intervention are the subjects of disempowering illness identities, which are imposed upon them by the humanitarian actor. Debrix asserts that this is due to the way in which medical humanitarian organisations such as MSF reshape the space in which they operate.<sup>24</sup> Debrix delineates two categories of geopolitical space that continuously co-exist. ‘Striated space’, a concept delineated by Deleuze and Guattari

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<sup>22</sup> Robins, p. 128

<sup>23</sup> Rose, p. 6

<sup>24</sup> Debrix, p. 827

(1980), describes the structuring of territorial boundaries based on planned strategies of inclusion and exclusion as determined by the State apparatus. 'Smooth space' is the unbounded space that exists when the State apparatus does not intervene. Transnational medical humanitarian organisations such as MSF, in seeking to 'provide assistance to populations in distress' regardless of nation state boundaries, occupy space transversally. In order to define what constitutes 'populations in distress', MSF must occupy and chart new territories whilst escaping the established confines of existing spatial delineations. MSF defines 'populations in distress' as 'victims of natural or man-made conflict and the victim(s) of armed conflict'.<sup>25</sup>

By forming distinctions between those populations that require assistance and those that do not, Debrix asserts that MSF acts beyond state boundaries but not beyond the boundaries of striated space. In other words, a necessary feature of medical humanitarian intervention is that it must define the space in which it operates in terms of medical observation and potential treatment. Therefore, individuals are included or excluded within the remit of the 'victim', based on health status. This reterritorialization of space creates the socio-spatial conditions necessary for defining the 'humanitarian zones' in which humanitarian actors can operate. According to Debrix, the populations that reside within these humanitarian zones are subject to the imposition of new territorial markings and social identities that necessarily accompany the formation of new spatial boundaries. In the case of the humanitarian aid recipient, Debrix proposes that the identity in question is that of the 'hapless victim' who resides within the 'space of victimhood'. Debrix argues that one remains as a 'victim' until one is 'rescued, cured or it is safe to escape the

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<sup>25</sup> MSF Charter accessed via MSF website [online] 'MSF Charter'2018, [cited 4<sup>th</sup> April 2018] Available from <<http://www.msf.org/en/msf-charter-and-principles>>

humanitarian zone'.<sup>26</sup> Debrix asserts that the social identity of the 'victim' is the one that must be conveyed to the global media, in order to raise awareness of humanitarian crises and garner funding in support of intervention. However, in asserting that one remains a victim until one is rescued, cured or the humanitarian zone is 'made safe', Debrix assumes that the identity label of the 'victim' remains fixed until the medical humanitarian actor works to alter this identity and impose that of the 'non-victim' in its place. Debrix offers no conceivable capacity in which self-empowerment of the 'population in distress' may be facilitated, rather than imposed, by the humanitarian actor.

Redfield elaborates on the concept of the 'victim' as a human being reduced to and maintained at a state of 'bare life'.<sup>27</sup> Redfield draws on Giorgio Agamben's redefinition of biopower, which aligns with the concept of sovereignty. Agamben notes the way modern power structures have the capacity to control life by excluding it from meaningful social and political existence.<sup>28</sup> This analysis draws on the distinction between categories of life originally established through the Ancient Greek terms of *zoë* (the simple biological fact of life, which implies no guarantees about the quality of life lived) and *bios* (a biographical life that is properly formed through events). Redfield defines a humanitarian crisis as 'a perceived rupture that invites humanitarian response'.<sup>29</sup> In such situations, medical humanitarian intervention is able to preserve existence at the level of *zoë*, but at the possible expense of 'deferring actions that support a mode of being more consistent with human dignity, or *bios*'.<sup>30</sup> Redfield suggests that, by virtue of working in situations of crisis, medical humanitarian organisations are necessarily concerned with afflictions of immediate

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<sup>26</sup> Debrix, p. 839

<sup>27</sup> Redfield, p. 340

<sup>28</sup> Robins, p. 130

<sup>29</sup> Redfield, p. 328

<sup>30</sup> *Ibid.*, p. 330

biological necessity whereby 'the figure of the human emerges from behind that of the citizen, in a bodily condition exposed by crisis'.<sup>31</sup>

The example of a refugee camp is employed by Redfield to demonstrate the limitations of an imposed biological identity in a crisis situation. According to Redfield, in refugee camps 'there are individuals to weigh, inoculate and categorise by the circumference of their upper arms'.<sup>32</sup> This assumes that the use of basic biological processes to constitute an identity is the reserved domain of the humanitarian actor; the same biological knowledge cannot be utilised by the respective individuals to form their own social identity. This is perhaps due to a lack of hermeneutic resources, on the part of both the humanitarian actor and the aid recipient, with which to conceptualise an empowering identity based around biological processes. Redfield assumes that this hermeneutic injustice, a concept outlined by Fricker (2007) and discussed in further detail below, is both asymmetric and irreparable within the confines of a crisis situation.<sup>33</sup>

In situations of humanitarian crisis that require long-term involvement, such as MSF's establishment of ARV treatment programmes in South Africa, Redfield notes that 'life in the sense of *zoë* only emerges as a problem from within bios'.<sup>34</sup> In other words, a reduction to a biological identity is only degrading when one has previously been used to claiming a respected identity. Links can be drawn between Redfield's example of displaced persons who come to occupy refugee camps, and people living with HIV/AIDS (PLWHA) in South Africa who become isolated from their communities on the basis of their biological health status. Redfield suggests that identities formed on the basis of health status lead to an essential reduction to the

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<sup>31</sup> *Ibid.*, p. 341

<sup>32</sup> *Ibid.*, p. 342

<sup>33</sup> Miranda Fricker, *Epistemic Injustice: Power and Ethics of Knowing* (Oxford: Oxford University Press, 2007)

<sup>34</sup> Redfield, p. 347

bare state of the species body—a process that separates individuals from the conditions necessary for human dignity. In focusing on maintaining the species body, humanitarian actors can only sustain life at a state of *zoë*. Therefore, those that remain inside the designated ‘humanitarian zones’ are preserved at a state of ‘bare life’ but are not afforded progression to *bios* through the exertion of humanitarian efforts.

With this in mind, the following sections will seek to challenge the concept that ‘humanitarian zones’ are necessarily ‘spaces of victimhood’. Humanitarian organisations such as MSF can facilitate the capacity for self-empowerment by allowing for the formation of constructive power relationships between recipients of intervention based around a biological conception of identity. The assumption that hermeneutic injustice concerning the biological body is irreparable in situations of crisis will also be challenged by demonstrating the ways in which humanitarian organisations can adapt to and address conceptions of the biological body. This will be addressed through the use of illness narratives from recipients of MSF intervention.

### **Introducing the Ritual Process: Illness Narratives**

The following primary accounts, published on the MSF website, have been chosen to articulate the transformational identity change that the MSF/TAC programmes had on the lives of the South African citizens they affected. These particular accounts demonstrate the category of illness narrative that sociologist Arthur Frank describes as a ‘quest narrative’.<sup>35</sup> The quest narrative accepts illness as a breakdown of body or health and uses the illness experience as a means of finding an alternative way of

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<sup>35</sup> Arthur Frank, *The Wounded Storyteller: Body, Illness and Ethics*, (University of Chicago Press: London, 1995) p. 115

being in the world. This narrative type is defined by the ill person's belief that there is something to be gained from the illness experience.

The outcome of the illness experience, and the journey undergone to achieve it, emerge retrospectively. The following narratives from MSF patients depict the journey undertaken to reconceptualise one's identity on a biological basis, and the responsabilised community relationships that were the subsequent outcome. These illness narratives underline the journey from physical existence (*zoë*) to qualified life (*bios*) and epitomise the collective cultural repertoire of similar narratives that exist in this area.

Phumizile Nywagi:

I'm Phumizile from Cape Town in the Western Cape. I was diagnosed in 2001 three days after my birthday. I was very sick. When you get sick you just ignore it. You say 'Oh it's just the flu'. You're in the denial stage. You say your neighbour is a witch[...] We thought this disease belonged to other people elsewhere in Africa. From my point of view HIV is real, it's here. I never thought I would be here today. I couldn't stand. I was sick. MSF told me my CD4 count was 110 and my viral load was 710'000. Then I started ARV's with MSF in Khayletisha. Now I'm strong.

Now I am sharing my experience of sickness, ARVs and health with my friends, family and community at large [...] I have had no problems in taking the ARVs and am working with TAC/MSF in my community. I encourage everyone to learn as much as they can about ARVs and to educate those around them about ARVs.<sup>36</sup>

Zoleka Lobi:

I was not happy at work, I was always scared that someone would find out and that I would be kicked out of my job anyway.

I decided to go to a clinic to find out if there were social workers that could help me. It is then that I learned more about HIV. I was counseled on how to live with HIV and they explained to me that having HIV was not the end of my life.

[...] I have been on antiretroviral treatments funded by MSF at Khayelitsha clinic. It helped to be in TAC because by the time I started with my treatment I was already educated about how the drugs work. I knew about side effects and how they can be managed and I have not had any since I started [...] Sometimes they forget I have HIV. At first they have been very scared by President Mbeki saying ARVs are toxic and my mother did not want me to take them. Now she is the one who reminds me first to take my medication.

You can see how my life has returned to normal even though I am living with HIV. I invite you to join MSF and TAC. If you cannot join TAC immediately, please join a support group and learn about treatments. It is a good way to learn to deal with HIV.

<sup>36</sup> MSF website [online] 'ARV's Saved My Life' by Phumizile Nywagi, 2003 [cited 4<sup>th</sup> April 2018] Available from <<http://www.msf.org/en/article/arvs-saved-my-life>>

In MSF and TAC you learn a lot about being a leader, taking responsibility. It also enriches your life if you are doing something for the community.<sup>37</sup>

Turner's concept of the ritual process will be applied to the aforementioned narratives, following the example set by Steven Robins (2008). Robins used this model to demonstrate the identity change of PLWHA in South Africa after apartheid, although without the particular focus on biocitizenship that will be applied here. The ritual process consists of three stages, originally identified by Arnold Van Gennep: separation, liminality and communitas, and finally reintegration.<sup>38</sup> 'Ritual' in this context relates to the structure and role of symbolism in Ndembu tribal practices, which Turner has applied to determine three distinct stages of identity transformation that occur in transmuting episodes of one's life. Analogies can be drawn between these stages and the stages in identity transformation undergone by PLWHA.

### **Separation: The Space of 'Victimhood'**

Separation is the first stage of the ritual process and describes a state of behaviour 'signifying the detachment of the individual or group from an earlier fixed point in the social structure'.<sup>39</sup> As Robins notes, the forms of stigma and isolation that PLWHA experience are analogous with this stage of the process.<sup>40</sup> This isolation is often the product of socio-cultural practices that are influenced by national and local barriers to understanding HIV/AIDS.

Zoleka describes the fear associated with the wider community finding out that she was HIV-positive, and her subsequent departure from her job. This demonstrates a detachment of oneself from a fixed point in the social structure—

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<sup>37</sup> MSF website [online], 'Accept Responsibility for AIDs Not Fear by Zoleka Lobi, 2003 [cited 4<sup>th</sup> April 2018] Available from <<http://www.msf.org/en/article/accept-responsibility-aids-not-fear>>

<sup>38</sup> Arnold van Gennep, *The Rites of Passage*, (University of Chicago Press: Chicago, 1960), p. 4

<sup>39</sup> Victor Turner, *The Ritual Process: Structure and Anti-Structure*, (New York: Cornell University Press, 1969), p. 94

<sup>40</sup> Robins, p. 137

both from the workplace environment and consequently from one's previous standing in the social community. Phumzile attributes his initial symptoms to witchcraft—'you say your neighbour is a witch'. Witchcraft in South African townships represents an established set of cultural conditions whereby illness was understood to be the result of *abathakathi* (witchcraft).<sup>41</sup> Indeed, Fox notes that the latent metaphysical assumptions surrounding causes of HIV/AIDS reflect elements of a 'traditional African cosmic view' that 'illness, sterility, failure, impoverishment [...]—all the negative, disappointing experiences of life—are caused by witchcraft or sorcery'.<sup>42</sup>

In this case, the 'space of victimhood' that Debrix suggests is perhaps more applicable to acute situations of crisis where the pre-existing social order has been completely overturned—either as the result of natural disaster or warfare. In such cases, the 'humanitarian zones' that MSF create are more aligned with humanitarian space as 'agency space'. In this case, 'agency space' is aligned with the Deleuzian concept of 'striated space' in so far as the humanitarian actor is responsible for defining the population in need of assistance:

The humanitarian agency is at the centre of this definition, with humanitarian space delineating the agency's ability to operate freely and meet humanitarian needs in accordance with the principles of humanitarian action.<sup>43</sup>

In acute settings of humanitarian crisis, marginalised individuals are not separated from the pre-existing social structure, as this structure has often been completely overturned; no earlier fixed point remains from which the individual can draw reference to their previous identity. In acute crisis situations such as natural disasters

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<sup>41</sup> Robins, p. 137

<sup>42</sup> Fox, p. 154

<sup>43</sup> Sarah Collinson, Samir Elhawary, 'Humanitarian Space: A Review of Trends and Issues, Humanitarian Policy Group ODI, 2012 [online] [Cited 4<sup>th</sup> April 2018] Available from <[www.odi.org.uk/hpg](http://www.odi.org.uk/hpg)>

or armed conflict, often entire communities are fractured, destroyed or displaced. Therefore, MSF is able to establish its own social structure within the confines of a designated 'humanitarian zone'.

In the case of the HIV/AIDS epidemic in South Africa, MSF was attempting to integrate into an environment where individuals had become 'separated' from a pre-existing social order that not only remained present but was responsible for the marginalisation of individuals based on their health status. This is partially reconcilable with Redfield's view that 'life in the sense of *zoë* only emerges as a problem from within *bios*'.<sup>44</sup> Individuals who were actually or potentially HIV-positive were isolated from the communities of which they were once part. However, the prevailing power structure responsible for the imposition of illness identities was not the humanitarian actor, but the power relations that existed between individuals in affected communities. This was influenced both by cultural beliefs and the sovereign power of the nation state in propagating its denialist stance. In this case, the role of MSF is more reconcilable with humanitarian space as 'affected community space'. The latter role can be defined as follows:

delineating the ability [of the affected community] to uphold their right to relief and protection. The humanitarian agency is still essential; however, it recognises the role that other actors play, including the affected community themselves, in meeting humanitarian needs.<sup>45</sup>

This recognises the role of the local and national barriers established by the state apparatus and the local community in defining the identity of marginalised individuals. Therefore, the new identity created for those individuals as 'victims' was not, as Debrix suggests, imposed by MSF. Instead, it was the product of pre-existing socio-cultural conditions. Rather than creating a disempowered 'space of

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<sup>44</sup> Redfield, p. 347

<sup>45</sup> Collinson, Elhawary, p. 1

victimhood', MSF had to enable the conditions necessary for active health responsibility. Doing so had to include the redefinition of the 'space of victimhood' into a 'biocommunity' of individuals, whereby 'in such spaces of support, non-citizens have unprecedented opportunity to claim new identity around their politicised biology'.<sup>46</sup> To achieve this, MSF had to address gaps in the hermeneutical framework of conceptualising the body, in order to facilitate an empowering biological identity that was neither imposed solely through humanitarian efforts, nor a demeaning reduction to the species body.

### **Liminality and Communitas: 'Threshold People'**

The second stage of the ritual process encompasses two areas of identity transformation. The first, 'liminality'—derived from the Latin word for 'threshold'—describes the ambiguities in the qualities of the ritual subject; the cultural realm that they are about to enter has few or none of the attributes of their past state.<sup>47</sup> Interventions put in place by medical humanitarian actors at this stage can act to challenge hermeneutic injustice with regards to biological conceptions of the body.

Hermeneutic injustice, first delineated by Miranda Fricker, describes a gap in the collective interpretative resources that mean that either patients, healthcare personnel, or both, do not have access to the conceptual framework that would allow them to make sense of their social experience.<sup>48</sup> Redfield suggests that hermeneutic injustice concerning the biological body is irreparable in situations in which humanitarian intervention is necessary. To a certain extent, Redfield's claim is justified. There are many documented cases, particularly with regards to the

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<sup>46</sup> Joao Biehl, 'The Activist State: Global Pharmaceuticals, AIDS and Citizenship in Brazil', *Social Text*, 22(2004), 105-132, (p. 122)

<sup>47</sup> Turner, p. 94

<sup>48</sup> Fricker, p. 1

HIV/AIDS epidemic in sub-Saharan Africa, of humanitarian intervention in which the humanitarian bodies involved have utilised biological knowledge whilst reserving it as the sole domain of the humanitarian actor.

For example, Dr Okot-Nwang one of Uganda's leading TB specialists, expressed his frustration at the involvement of a group of American researchers from a humanitarian organisation that 'had flown in from an American university, swooped into his wards and taken blood samples from the patients who felt that magico-religious forces were responsible for their illness'.<sup>49</sup> Those that tested positive for HIV had their TB regimes terminated and were started on ARV therapy. He notes that 'many of those patients died' because the humanitarian actors failed to recognise that there is often an overlap in blood results between patients who are positive for both HIV and TB, and those that are positive for TB but negative for HIV.<sup>50</sup> This illustrates wider hermeneutic injustice on both the part of humanitarian actors and recipients of humanitarian intervention. NGOs demonstrate an inability to conceive that local medical authorities may be in the best position 'to have access to crucial evidence given their marginalised locations'.<sup>51</sup> Equally, recipients of humanitarian aid in the global South often lack the necessary framework to articulate their health status due to a lack of a biomedical paradigm. As Redfield notes, the balance of hermeneutic injustice is asymmetric; patients will suffer more from a lack of a hermeneutic framework than their humanitarian counterparts.

However, MSF's involvement in combatting the AIDS epidemic in South Africa allowed for the sharing and facilitation of biomedical conceptions of the body through

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<sup>49</sup> Helen Lauer, 'How epistemic injustice in the global health arena undermines public healthcare delivery in Africa' (unpublished commentary, 2017) [accessed 04 April 2018] Available from <<http://www.immunity.org.uk/wp-content/uploads/2017/09/Rio-handout--Laurer-with-Shentons-commentary-16.6.17.pdf>>

<sup>50</sup> Ibid.

<sup>51</sup> Ibid.. p. 6

which recipients of medical intervention could begin to form an empowering identity. For example, Phumzile went from a belief that AIDS was caused by witchcraft to accepting a biological conception of illness. This is evidenced by the way in which Phumzile correctly utilises immunological discourse to chart his illness and relate it to his lived experience— ‘My CD4 count was 110 and my viral load was 71’000’. Additionally, Zoleka explains that by the time she started ARV treatment, she was ‘already educated about how drugs work’. In order to demonstrate that changes in the prevailing attitudes were brought about by a new understanding of a biomedical paradigm, it is essential to understand the projects that MSF facilitated.

One such project was the Ulwazi project in Khayletisha, which was sponsored and run by MSF. This involved training members of the community who were HIV-positive to understand the biological basis of their illness through various resources including group discussions and immunology videos such as ‘Beat it, HIV and AIDS’.<sup>52</sup> One community member involved was Vuyiskea Dubal. She detailed how MSF volunteers talked to her knowledgeably and gave her an understanding of the ‘virus of HIV’ and its effects on her body.<sup>53</sup> Vuyiskea was then enabled to ‘train, educate and support’ other community members in understanding the biological processes behind HIV/AIDS. MSF’s empowerment of members of the community represents an attempt to establish a hermeneutic framework through which humanitarian actors can learn to value knowledge held by recipients of humanitarian aid about their own bodies. It is an acceptance on the part of MSF that biological understanding should not remain the privilege of the humanitarian actor, but should be shared between individuals to facilitate the sharing of power based on biological bodily conceptions.

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<sup>52</sup> Fox, p. 144

<sup>53</sup> *Ibid.*, p. 139

This leads to the latter half of this stage of identity progression, that of 'communitas', which emerges as a result of the processes in the liminal period. 'Communitas' describes a rudimentarily structured and relatively undifferentiated community of equal individuals.<sup>54</sup> This is demonstrated in the establishment of MSF/TAC support groups as non-hierarchical social spaces, within which individuals could both express and unite in biological conceptions of their identity. This challenges Debrix's claim that humanitarian organisations cannot facilitate self-empowerment within 'humanitarian zones'. The Ulwazi project encompassed the meeting of HIV-positive individuals from the community. During these meetings individuals could share their stories of HIV diagnosis and treatment. The sociologist Renee Fox documented these meetings as an 'affirming' experience for community members.<sup>55</sup> Rather than confirming Redfield's assertion that biological identity in the humanitarian context represents a demeaning reduction to the 'species body', the aforementioned examples demonstrate a claim to citizenship within a community brought together by an acceptance of individual biological identities. This is more consistent with a life of human dignity than with Redfield's disempowering perception of the biological body.

### **Reintegration: Empowering Conceptions of the Biological Body**

The construction of non-hierarchical social spaces such as MSF/TAC support groups facilitates the third and final stage of identity progression in an individual's transition from *zoë* to a more qualified state of *bios*; that of reintegration. In this stage, the ritual subject is in a relatively stable state once more, and by virtue of this has rights and

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<sup>54</sup> Turner, p. 96

<sup>55</sup> Fox, p. 140

obligations towards others within the community of which they are part.<sup>56</sup> With regards to the HIV/AIDS illness trajectory, this social stage parallels an individual's initiation onto ARV treatment, a subsequent increase in CD4 count, and a decrease in viral load.

As Steven Robins notes, individuals at this stage now possess the capacity to become 'activist-citizens', empowered with the knowledge to understand and speak out about HIV/AIDS.<sup>57</sup> This represents a legitimising identification of one's social identity with one's biological health status, as opposed to a demeaning reduction to the 'species body'. Phumzile talks of 'sharing [his] experience of ARV's and health with [his] family, friends and the community at large', and the importance of doing so for the benefit of the wider social polity. Equally, Zoleka notes MSF and TAC's facilitation of leadership and responsibility, adding, 'it also enriches your life if you are doing something for the community'. This reinforces the notion of one's obligation towards others as a responsabilised health citizen.

The notion of 'responsibility' is imparted by the humanitarian actor onto the recipients of intervention. In this case, this encompasses the kinds of responsabilised health behaviours deemed necessary for effective HIV/AIDS treatment, such as the use of condoms, adherence to ARV regimens and a collective responsibility to dispel the stigma surrounding HIV/AIDS. Although this is an example of an asymmetrical power relationship between an established body and the population for which it is accountable, it is not entirely consistent with sovereign power. Sovereign power maintains a focus on the ability to 'let live or make die'.<sup>58</sup> By contrast, the power of the humanitarian body is more concerned with the expansion and protection of life. It achieves this by facilitating power relationships between individuals and their

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<sup>56</sup> Turner, p. 95

<sup>57</sup> Robins, p. 137

<sup>58</sup> Cisney and Morar, p. 2

networks. To this extent, the power relationship between MSF and members of MSF/TAC support groups is more consistent with Foucault's concept of biopower as power transmitted between individuals, than with Agamben's reconceptualization of biopower drawn upon by Redfield. MSF also seeks to emphasise the dignity attributed to the biological life; it is viewed not only as reconcilable with one's wider social identity, but as an integral part of it. This suggests that as humanitarian actors increasingly seek to tackle longer term health conditions, the power relationships between transnational actors, recipients of intervention and the State require revised analysis that can account for these changing dynamics.

The most widespread example of the facilitated transition to self-empowered, 'activist citizens' afforded by the MSF/TAC alliance in South Africa was documented by the sociologist Renee Fox during her visit to an MSF/TAC rally in September 2003.<sup>59</sup> The rally aimed to demonstrate support for the South African government's plans to implement an 'operational ARV treatment program'. Participants and supporters who attended the rally wore T-shirts emblazoned with the slogans: 'HIV-positive' (making one's biological status synonymous with one's outlook on life), and 'Two Pills a Day Saves Lives'.<sup>60</sup> Nelson Mandela had been photographed wearing a 'HIV-positive' T-shirt at a similar MSF/TAC rally in 2002.

The aforementioned examples demonstrate a powerful and empowering identification with one's biological body that typifies the creation of a biological citizen. According to Rose and Novas, the conditions necessary for the creation of biological citizenship include both a reshaping of an individual's relationship with themselves, and a reshaping of the way in which a person is understood by the

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<sup>59</sup> Renee Fox, p. 147

<sup>60</sup> Ibid.

prevailing authorities.<sup>61</sup> The former requirement is demonstrated through the use of biomedical concepts to exemplify aspects of an individual's identity (such as ARVs), which are then disseminated as dignified discourse through authoritative channels—in this case a social movement rally. With regards to the latter requirement, the biomedical understanding facilitated by MSF enabled individuals to demand resources through the employment of biological discourse; doing so enabled the reconceptualisation of HIV/AIDS by prominent political figureheads. The ability of MSF to facilitate individuals and communities to demand biomedical resources, as opposed to acting as an independent advocate, is both necessary and empowering given that MSF never intends its actions to erase the need for long-term political intervention.

### **The Limitations of Biocitizenship**

Turner's model of ritual processes helps to account for how MSF's involvement in South Africa facilitated a collective identity transformation in recipients of ARV therapy; from individuals existing in a state of depreciated social existence, to active communities of citizens with an autonomous claim to their biological health states. MSF activists in South Africa claim that they provide 'much more than the promise of AIDS drugs, condoms and more equitable access to healthcare'.<sup>62</sup> Any attempts to reconcile this claim with conventional rights-based social movements largely underestimate the impact of illness identities on humanitarian action in resource-poor settings. Although rights-based struggles form a large part of MSF/TAC AIDS activism in South Africa, so do the creation of collectively shared concepts of stigmatisation and illness. It is the impact of marginalisation from the wider social

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<sup>61</sup> Nikolas Rose, Carlos Novas cited in *Global Assemblages*, p. 455

<sup>62</sup> Robins, p. 140

polity based on pseudo-biomedical discourse that more mainstream social movement theories fail to account for.<sup>63</sup>

The use of Turner's model was not simply an attempt to draw parallels between illness narratives and the linear trajectory of biological recovery. It is evident from the ethnographic accounts that biomedical intervention played a significant role in the identity transformation of respective individuals. However, it is equally clear that socio-cultural and religious beliefs also played an integral part. This highlights one of the essential problems in using the term 'biocitizenship' to describe the collective identity transformation in communities brought together around specific biomedical classifications. Biocitizenship can be a reductive lens through which to view an individual's identity, given the increased emphasis placed on the biological proponent of a multifaceted whole. This essay will now examine the limitations of the term 'biocitizenship' as it currently stands, before demonstrating why biological citizenship still provides a useful starting point for assessing the impact of biomedical technology on the identities of individuals it affects, particularly those in resource-poor settings.

There can be no doubt that, given the ever-increasing utilisation of biomedical discourse, Rose and Novas are correct to suggest that 'collectivities organised around specific biomedical classifications are increasingly significant'.<sup>64</sup> Some examples cited by the former include the founding of the Manic Depression Fellowship in 1983 and online support and mobilisation forums for patients with Huntington's disease and Canavan's disease.<sup>65</sup> Rose and Novas argue that this form of citizenship is inherently active and empowers the individual with the capacity to

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<sup>63</sup> Ibid.,

<sup>64</sup> Rose and Novas cited by Alexandra Plows and Paul Boddington, 'Troubles with biocitizenship?' *Genomics, Society and Policy*, 2(2006), 115-135, (p. 118)

<sup>65</sup> Ibid.,

demand rights, take on duties and to exert both prudence and choice.<sup>66</sup> However, Rose and Novas' account of biocitizenship is overly optimistic.

When analysed from a disability rights perspective, 'biocitizenship' acts as a blanket term that reifies a complex debate about the social importance afforded to one's biological health status. Those diagnosed with a specific disability or disease may form activist communities that make demands based on their health status. The individuals who constitute this collective may view their biological identity as central to their existence; others may completely reject a biological framing of their identity, viewing it as a single part of a complex social picture. A current example of this is found in online communities and groups representing patients with Spinal Muscular Atrophy (SMA). Whilst there are many activist SMA communities whose identity is framed largely around their biological health status in an effort to secure state funding for the treatment drug Spinraza, there are equally many other communities and resources available that encourage people to see patients with SMA as people, whose existence is not defined by their biological or pharmaceutical status.<sup>67</sup> Of course, this is not a mutually exclusive dichotomy, but the former example helps to exemplify the complexity of using the term 'biocitizen' as an all-encompassing identity.

Susan Reynolds Whyte further elaborates this point, by suggesting that many of the examples used by Rose and Novas, particularly where parallels are drawn between biological citizenship and the rise of genomic technology, are those of online support groups.<sup>68</sup> Consequently, this offers a decontextualized view of the illness experience without any means of assessing the concurrent social, economic

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<sup>66</sup> Plows and Boddington, p. 119

<sup>67</sup> TreatSMA Homepage [online]. Treat Spinal Muscular Atrophy, 2020, Updated November 2020 [accessed 24 November 2020] Available from: <<https://www.treatsma.uk/>>

<sup>68</sup> Susan Reynolds-Whyte, 'Health Identities and Subjectivities: The Ethnographic Challenge', *Medical Anthropology Quarterly*, 23(2009), 6-15, (p. 11)

and cultural frames that contribute towards an individual's sense of identity. It also raises another important issue; those individuals who create and participate in active forums, whether online or in the community, are often those citizens who have internalised the concept of responsible health behaviour and possess the necessary means to act on this concept. By contrast, those individuals who do not assert their illness identity—either due to lack of desire, or as a result of external factors such as poverty, homelessness or addiction—are labelled as 'problematic people' and excluded from any notion of biological citizenship. In this way, biocitizenship may become another means of stratifying populaces based on one's ability to access and comprehend biomedical discourse. Dr Eric Goemaere, head of MSF South Africa, acknowledged this by asserting that 'ARV's can also become a conduit for the medicalisation of poverty'.<sup>69</sup> In other words, biotechnology and one's ability to advocate for it may become another means by which those that lack the capacity for advocacy are marginalised from the social polity.

Although MSF aims to consciously counter disempowering and normalising biomedical discourse, it is becoming apparent that in the new context of collaborative medicine, patients can no longer passively occupy the 'space of victimhood' proposed by Debrix. Instead, 'the responsibility for adherence to treatment is given to the recipient within a clear framework of empowerment and support'.<sup>70</sup> The obligation to safeguard health is devolved to the patient as well as to the provider, but it is important to acknowledge the limitations of viewing the recipient 'other' solely through a reductionist biological lens. As Whyte suggests, one way in which to overcome this problem is to analyse biocitizenship through comprehensive

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<sup>69</sup> Eric Goemaere cited by Robins, p. 669

<sup>70</sup> Robins, p. 669

ethnography.<sup>71</sup> As this essay has attempted to demonstrate, a detailed narrative structure allows one to problematize biocitizenship and identity politics within a broader socio-economic and cultural framework. It attempts to encapsulate biocitizenship in such a way that allows for analysis of the wider fundamental differences that may underlie health inequalities.

### **Conclusion**

Biocitizenship remains a useful starting point for assessing the impact of biomedical technologies on the identities of those individuals that they affect. As humanitarian efforts focus increasingly on the concurrent management of both acute situations of crisis and the long-term management of chronic diseases, it is important to foreground that whereas active citizenship engagement may be impossible in the former situations, it is increasingly necessary in the latter. In situations of crisis that require long-term humanitarian action, it is imperative to recognise that recipients of humanitarian aid are not synonymous with the body politic of the disempowered victim, and as such possess the capacity to advocate for rights.

The HIV/AIDS epidemic in South Africa occurred within a unique cultural framework, underscored by the legacy of post-colonialism, the apartheid regime and a dominant social polity that stigmatised HIV/AIDS sufferers. As such, the health ideologies that MSF encountered were largely defined by the relationship between citizens and the state, and the struggle to receive state support from a 'denialist' government. However, it is possible to extend elements from MSF's projects in South Africa to other situations where long-term medical humanitarian involvement is necessary. One of MSF's current projects in India is focused on the prevention and

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<sup>71</sup> Reynolds-Whyte, p. 13

management of hepatitis C, a blood-borne infection that can become chronic in up to 85% of cases; up to 18 million Indians are currently infected.<sup>72</sup> Chronic hepatitis C (CHC) requires treatment with antiviral therapy for a minimum of two years. This prolonged treatment interval necessitates the kind of active engagement and responsabilised health behaviours that MSF was successful in facilitating in South Africa. In these situations, the paternalistic construct of the humanitarian actor imposing an identity on to recipients of medical humanitarian intervention is increasingly outdated. Optimal treatment outcomes in cases of chronic disease management require the facilitation of power relationships within and between individuals and their respective communities.

The construct of 'biocitizenship', although imperfectly delineated, offers a useful framework for assessing the empowering collectivities that can arise based on a shared conception of biological identity. However, caution should be used when applying the term as a generalised body politic. In an era where one's biology is increasingly open to remediation, it is important for humanitarian actors to facilitate biological understanding within the 'humanitarian zones' in which they operate. The price of failing to do so could potentially lead to the commodification of biomedical technologies in the global South, and further contribute to global inequality.

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<sup>72</sup> MSF Website [online], 'Hepatitis', 2018, Available from <<https://www.msf.org.uk/issues/hepatitis>>, [Accessed 15 May 2018]

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