

## DO AID AGENCIES HAVE AN ETHICAL DUTY TO COMPLY WITH RESEARCHERS? A RESPONSE TO RENNIE<sup>1</sup>

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### ABSTRACT

Medical AID organisations such as Médecins Sans Frontières receive several requests from individuals and international academic institutions to conduct research at their implementation sites in Africa.

Do AID agencies have an ethical duty to comply with research requests? In this paper we respond to the views and constructed theories (albeit unfounded) of one such researcher, whose request to conduct research at one of our sites in the Democratic Republic of Congo was turned down.

We were very surprised to read the article titled: ‘Is it Ethical to Study what Ought Not to Happen’.<sup>2</sup> The letter we wrote to Stuart Rennie in late 2004 outlining our reasons for not wanting to participate in his study was just that – a letter from one individual to another, briefly outlining an opinion about their study. We did not expect that this personal response would be selectively quoted and wilfully misinterpreted in order to construct a largely baseless criticism. Nor did we imagine that the contents of this letter would be exaggerated to the point of becoming an ethical viewpoint, let alone an international organisational policy. Rather than entering into a discussion with Médecins sans Frontières (MSF) on this important issue, Rennie preferred to construct a theory on what MSF’s ‘vision’ would be on various issues and than to criticise this ‘supposed vision’ for the sake of publishing a paper.

<sup>1</sup> To clarify or further discuss any of the points raised in this article, please contact the corresponding author directly using the contact information supplied at the end of this piece.

<sup>2</sup> S. Rennie. 2006. Is it Ethical to Study what Ought Not to Happen. *Developing World Bioethics* 2006; 6: 71–77.

We will leave aside the important question of rationing, for which we hope the editors of *Developing World Bioethics* will, sometime in the future, allow space for a more legitimate and evidence-based discussion. We will limit ourselves instead to addressing the two main themes that Rennie’s paper evoke for us: do aid agencies have an ethical duty to comply with researchers, and does calling something an ethical issue make it one?

### DO AID AGENCIES HAVE AN ETHICAL DUTY TO COMPLY WITH RESEARCH REQUESTS?

Starting from the title of his article: ‘Is it Ethical to Study what Ought Not to Happen’, Rennie sets up the argument that MSF single-handedly halted his research on ethical grounds. We did neither.

MSF did not at any stage question the right of the University of North Carolina to undertake this study in Kinshasa or elsewhere, nor the scientific interest that it may entail (although admittedly we

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did wonder why the department of dental ecology was undertaking research on HIV in the Democratic Republic of Congo). Our reservations were entirely limited to MSF not being interested in participating in the study.<sup>3</sup> Given that Rennie considers that this research question is of considerable importance, one would expect his first response to be to find another study site.

We also did not cast any ethical judgement on the objective of the study. Rennie argues that it is a matter of 'simple transitive logic'<sup>4</sup> that if you view treatment access rationing as unethical then you view research into rationing as 'morally corrupting'.<sup>5</sup> This is pure hyperbole: holding an opinion against rationing is not the same as ethically objecting to research into rationing. Pre-empting this criticism, Rennie states that: 'One could argue that MSF-Belgium is merely stating their own opinion rather than making a general ethical judgment about treatment access rationing'.<sup>6</sup> His rebuttal? 'The language of the letter does not easily support this interpretation'.<sup>7</sup> The language of MSF's letter made not a single reference to the word ethics (except when citing the title of his research protocol). Readers can judge the language of the letter for themselves: for the sake of transparency, we will make the full text available.<sup>8</sup>

In fact, the only objections we raised that can, without spin, be considered to have ethical weight were with respect to the study design, which lacked any mechanisms to ensure community benefit and did not involve national implementing partners. Rennie did not respond to either of these concerns, and has selectively omitted these points in his article.

Another baseless claim Rennie makes as a reason for MSF's non-involvement in the study is fear of: 'Damage to MSF Belgium's public image'<sup>9</sup> and that, 'any connection between MSF and rationing would

send the wrong message to the world — undoubtedly including MSF's financial contributors'.<sup>10</sup> There is nothing in our letter, or indeed in his article, upon which this claim can be justified, and it is certainly not the case that any of MSF's operational activities are defined by concerns about public image.

The question seems to boil down to this: does MSF have an ethical obligation to comply with the requests of researchers? We do not believe this to be the case. Our first duty is to deliver medical assistance to people in need. This does not mean we are against all forms of research, just that we are not obliged to participate in it.

Perhaps it could be argued that implementing agencies do have some sort of obligation, when placed in a unique position, to provide answers to urgent and important questions, but in this case we did not believe the research was of the most pressing importance. Nor are we uniquely placed to provide the answer: the unfortunate reality is indeed that universal access to antiretroviral therapy is still a long way off, and research into rationing can be undertaken with hundreds of groups in most countries of the developing world. And, preferably it will involve local partners who are most acutely affected by the problem, rather than international NGOs whose first priority is not research.

## DOES CALLING SOMETHING AN ETHICAL ISSUE MAKE IT ONE?

Rennie makes the point that 'while it is uncertain that the letter accurately expresses the ethical position of MSF on treatment access rationing, it cannot be ruled out either'.<sup>11</sup> This makes for an extremely fragile foundation upon which to publish an article that is entirely about MSF's ethical position on rationing. We would like to take issue with a number of his assumptions.

'If not all can be saved, then none shall be saved'<sup>12</sup> is stated as MSF's position by the author, putting forward yet another baseless claim. Rennie elaborates by saying that MSF has 'a policy of waiting for new drugs to treat everyone rather than distributing

<sup>3</sup> Even this point is exaggerated. The letter states that we had 'serious reservations on this study being conducted at any MSF site'. This is translated by Rennie as 'I was forbidden to involve the local branch of MSF in my study. Not only that: it was stated that no MSF site anywhere in the world could be involved in my study'.

<sup>4</sup> Rennie, *op.cit.* note 2, p. 73.

<sup>5</sup> *Ibid.*: 73.

<sup>6</sup> *Ibid.*: 76.

<sup>7</sup> *Ibid.*: 76.

<sup>8</sup> Copies available from the corresponding author.

<sup>9</sup> Rennie, *op. cit.* note 2, p. 73.

<sup>10</sup> *Ibid.*: 73.

<sup>11</sup> *Ibid.*: 76.

<sup>12</sup> *Ibid.*: 76.

available resources'.<sup>13</sup> We have no such position or policy. The reality clearly shows that MSF has often been the first to dare to start antiretroviral treatment in many countries around the globe while other actors have refused to act.<sup>14</sup>

We take further issue with the position ascribed to us, in a situation where there were not enough malaria drugs to go round, that: 'the ethically right response would be to wait to get more malaria drugs until all malaria patients can be treated'.<sup>15</sup> We believe, and stated so in our letter, that the solution to this dilemma does not lie in spending energy on conceiving strategies of rationing but rather in doing whatever one can to make sure that the drug supply meets the required demand. But this should be done at the same time as, not instead of, treating as many people as one can. Whether you are for or against rationing you still can, and should, act.

Rennie then raises what he calls an 'uncomfortable but undeniable fact'<sup>16</sup> – but also a wrong fact – that MSF is implementing AIDS treatment rationing. Within MSF's programmes, the medical and social criteria applied to determine who needs antiretroviral therapy are employed not as rationing criteria but as good medical practice and public health practice. Medical criteria (clinical staging, CD4 count, and viral load) are employed to ensure that only people who need to be treated are treated; social criteria, where they exist in MSF programs, are used as public health provisions to avoid providing antiretroviral therapy to patients with a high probability of non-adherence and in doing so promoting drug resistance.

To serve his argument, Rennie interchanges rationing of care, selection of beneficiaries, and setting of priorities. For MSF, these are very distinct concepts, if they are linked at all. Any organisation working in situations of humanitarian crisis is faced permanently with the cruel reality of insufficient means compared to the massive humanitarian needs. As one can observe from MSF's operations,

neither this incapacity to treat all, nor the lack of guarantee that treatment will be continued on the longer run, has prevented MSF from providing concrete and direct assistance to people in need. The selection-exercise this implies is done by MSF on a basis of programmatic criteria of (medical) vulnerability of population groups, intrinsic limits of MSF's expertise and capacity, and the feasibility of qualitative action.

Currently, around six million people in the developing world are in medical need of antiretroviral treatment. MSF is treating 56,000 patients in 28 countries. Does this mean that everyone who is not on treatment is the victim of MSF rationing? Rennie tries to argue this, but it is absurd to do so. It is certainly not, as Rennie claims, evidence of a 'new position'<sup>17</sup> or a 'volte face'.<sup>18</sup>

## FINAL REMARKS

Aid agencies have a duty to provide the best possible standard of care on the basis of the best available evidence. They should also constantly question how they intervene and learn from their actions and apply those lessons elsewhere. They do not, however, have a duty – ethical or otherwise – to comply with research.

We consider rationing as a tactical acceptance of injustice that aims to respond to imbalances by offering only limited assistance for a chosen few. Some may view this as a naive starting point, but that is what principles aspiring for justice should be inspired by. MSF believes that a technical approach to political distortions will only refine injustice. When people die, a technique that allows discrimination between who will die fairly or unfairly doesn't seem the right answer.

### Disclaimer

The opinions of the authors are theirs alone. They cannot be taken to represent the opinions of MSF as a whole, nor of the MSF Brussels-operational centre.

<sup>13</sup> Ibid: 76.

<sup>14</sup> E. Goemaere, N. Ford & S.R. Benatar. HIV/AIDS Prevention and Treatment. *Lancet* 2002; 360: 86–87.

<sup>15</sup> Rennie, *op. cit.* note 2, p. 76.

<sup>16</sup> Ibid: 73.

<sup>17</sup> Ibid: 74.

<sup>18</sup> Ibid: 74.

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