<u>C O M M E N T</u>

Ethical blind spots: John Cutler's role in India and Tuskegee

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The Tuskegee experiment has become an essential case study in the discussion of medical research ethics. The lessons learnt from it continue to be debated and written about. Briefly, the Tuskegee experiment, carried out over three decades till the early 1970's, was an observational study of African Americans who had syphilis. They were never told that they had the disease, nor were they provided with penicillin when the drug became available. The efficacy of penicillin in treating syphilis had already been established, initially among soldiers during World War II (1). On the basis of the experience with the army, the drug was then tried successfully among the civilian population (2). The fact that the Tuskegee study had been carried out was brought to light by a newspaper reporter in 1972, well after the Nuremberg Code (1948) and the Helsinki Guidelines (1963) had been framed, and also after the publication of the path-breaking Beecher Report (3). The news of the Tuskegee experiment gave rise to widespread outrage. It led to the formulation of the Belmont Report (1979) and President Clinton publicly apologised for the incident.

Later, news of the Guatemala experiments on syphilis, carried out from 1946 to 1948 by the same agency and involving some common investigators, surfaced. President Obama apologised for this. The details of the Guatemala experiments have recently been reviewed and the ethical implications of the experiments have been discussed (4). Briefly, 1308 research participants, including prisoners, soldiers and psychiatric patients, were intentionally exposed to sexually transmitted disease (STD) through commercial sex workers, most of whom were also intentionally infected with STD. In addition, 5128 subjects, who consisted not only of the members of the three groups mentioned earlier but also children, leprosy patients and personnel at the US base in Guatemala, underwent diagnostic testing, which included blood sampling and lumbar and cisternal punctures. When the report was released, a commentator compiled a list of the ethical shortcomings of the experiments: the absence of informed consent, adults and children being made to undergo invasive procedures, treatment of STD for only some of the participants, uninvestigated deaths, "abysmal" record-keeping and failure to disseminate the results (5).

One investigator who was involved in both the Tuskegee and Guatemala experiments (6) was John Cutler. John Cutler was Professor at the University of Pittsburgh and Acting Dean of the Graduate School of Public Health in 1968-1969, prior to which he had been an Assistant Surgeon-General in the US government. His involvement in both studies was in his capacity as an official of the US Public Health Service. When he died in 2003, at least one of his obituaries made no mention of his role in Tuskegee or Guatemala. It focused, instead, on his work at the university, his appreciation of the freedom of people across the world, as well as his efforts to ensure access to reproductive healthcare services for women not only in the US, but also in the developing world. He was described as a man who "... led the way in trying to prevent and control sexually transmitted disease throughout the world." A professor of Demography, of Indian extraction, at the University of Pittsburgh, Ravi Sharma, highlighted his passion for what he did with the following tribute: "To him, health was more than simply studying microbes. It was life." (7). On Cutler's death, his wife reportedly said that "her husband was always proud that he was able to raise the Indian flag in Simla, India, after the independence." (7)

In 1949, a paper entitled "Modern concepts of syphilis control" was published by the Health Department of the West Bengal government (8). John Cutler was listed as the first author. Judging by the affiliations of the authors, the paper appears to be driven by the venereal disease team of the South East Asia Regional Office of WHO. The first part of the paper consists of a historical overview of the treatment of syphilis. Mention is made of the study published in 1947 by Cutler and others (Arnold, Mahoney and Levitan), who had reported a low relapse rate (less than 5%) for patients of infectious syphilis treated with penicillin and followed up for six years. The paper goes on to state: "The development of an exceedingly innocuous and highly effective repository penicillin assures bacteriologic 'cures' for syphilis with one injection of 300,000 units in a high proportion of cases." It then asserts that single-injection penicillin therapy has the advantage of "securing the largest number possible of cured patients at minimum costs". Later in the paper, the authors caution us that "the moral aspects of venereal diseases must not enter the medical approach to this group of diseases. The patient is a sick individual who needs and can benefit by treatment". In a later paper published in 1954, Cutler continues to strongly advocate the use of penicillin across the spectrum of syphilitic diseases: "Its triple effect in the treponematoses - curative in manifest disease, abortive

in the incubation period, and prophylactic before exposure to contagion – has made it one of the important agents which can be used not only in the individual patient but also to treat population groups on a broad basis" (9).

The paper published by Cutler during his stay in India and the follow-up paper in the Bulletin of WHO raise some interesting questions. In terms of chronology, the papers were written after the Guatemala experiments, but following their publication, Cutler continued to be involved in the Tuskegee experiment, in which those diagnosed with syphilis were denied penicillin. By his own admission, Cutler had started prescribing penicillin for syphilis patients as early as 1947, and in 1949, he had strongly advocated the use of penicillin to treat syphilis in India. By 1954, he had compiled data on its effectiveness across the world. So, why did he and his colleagues fail to use penicillin in the Tuskegee study? How is it that an individual who felt so strongly for the freedom of a nation, and who propagated the use of penicillin to a population miles away from his home country, could not see the need for individual freedoms and failed to consider the rationale for the use of penicillin among the Tuskegee study population, who were being followed up at the same time? What made the two situations different? Was it an issue of prescribing therapies, on the one hand, and a singleminded obsession with research, on the other? Could this have led to "ethical disconnect"?

If anything, the episode is perhaps a reminder of the fact that we are all fallible and that we all have ethical blind spots. An awareness of this might allow us to guard against it and its consequences. So why do people behave in ways that are contrary to their ideals or principles? In an article by the American Psychological Association, Rebecca Clay quotes Tenbrusel and suggests that people have four ethical blind spots (10).

- *Ethical illusion:* This basically refers to the tendency to think that one is more ethical than one actually is. There is a disconnect between one's predicted behaviour and one's actual behaviour; while the former is driven by abstract reasoning, the latter is determined by practical issues, such as desirability, feasibility and actual ground realities.
- *Ethical fading:* This is a phenomenon characterised by the inability of individuals to see that a given situation requires an ethical judgment, and their preference for viewing the situation using other constructs.
- Dangerous reward systems: This notion is based on the premise that "the brain is good at paying attention to what it is incentivised to do". The incentives may be in the form of social or personal rewards. Thus, individuals may justify their actions on the basis of other factors while ignoring the fact that the primary motivation may be self-reward.
- Motivated blindness: This signifies that we do not see the unethical behaviour of others if it is not in our interest to do so. In this context, Pacholczyk quotes an Auschwitz survivor, who described the German ethical blind spot during the Second World War thus: "... most Germans didn't know

because they did not want to know. Because, indeed they wanted not to know....Those who knew did not talk; those who did not know did not ask questions; those who asked questions received no answers" (11).

Perhaps because it is hard to imagine that John Cutler continued to work on the Tuskegee experiment in isolation, without broader institutional support or the support of peers and donors, Susan Reverby, the historian who broke the news of the Guatemala experiments, spoke of the need to take a proper perspective of the situation: "Cutler and his colleagues thought they were doing really good science against a really dreadful disease.... I think it's incredibly dangerous to see Cutler as a monster, like Nazi doctor Joseph Mengele, and not understand the broader institutional support for what he's doing" (6).

The fact that individuals may have ethical blind spots does not condone unethical behaviour. As the Presidential Commission for the Study of Bioethical Issues stated in its report on the Guatemala experiments, "The Guatemala experiments involved gross violations of ethics as judged against both the standards of today and the researchers' own understanding of applicable contemporaneous practices. It is the Commission's firm belief that many of the actions undertaken in Guatemala were especially egregious moral wrongs because many of the individuals involved held positions of public institutional responsibility" (4). The report goes on to indict the researchers: "The experiments in Guatemala starkly reveal that, despite awareness on the part of government officials and independent medical experts of then existing basic ethical standards to protect against using individuals as a mere means to serve scientific and government ends, those standards were violated. The events in Guatemala serve as a cautionary tale of how the quest for scientific knowledge without regard to relevant ethical standards can blind researchers to the humanity of the people they enlist into research" (4).

I believe that those who teach ethics to health professionals must be aware of ethical blind spots for at least two reasons. First, as educators, they need to understand that an emphasis on broad hypothetical case studies might give rise to approaches that are at variance with the demands of actual practice. In actual practice, decision-making is contextual and governed by multiple considerations, rather than the linear logic of a case study. It will be a challenge to successfully engage students in considering specific, often uncomfortable choices that would reveal ethical blind spots and widen the ethical debate. Second, as educators, they need to sensitise themselves to their own individual ethical blind spots. How can we recognise these blind spots? While introspection will help, as Kamei suggests, we need our colleagues' help to visualise them (13).

Naturally, we will encounter certain challenges. We need to have systems that are open and transparent, as well as fair and unmotivated. This will not only bring overall systemic benefits, but will also prevent the backbiting that is becoming increasingly prevalent in academic circles.

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