

Correspondence

Building ethical solidarity between public health & the press against HIV/AIDS-related stigma

Sir,

Many in the public health, HIV/AIDS, and human rights communities and beyond have been stunned over the publication of a public notice bearing the name and personal details of an individual alleged to be “affected with HIV positive” appearing in *Mid-Day Magazine* (Mumbai) last May. In a country where four out of five Indians get their HIV-related information from the media¹, such incidents reflect the limits of our efforts in diverse quarters in reducing the stigma associated with HIV/AIDS and invite reflection on how we can do better. This letter draws renewed attention to the role of the media in perpetuating HIV/AIDS-related stigma in India, which reflect violations of the norms of ethical conduct of journalism. It shows the parity these principles have with the bioethical norms of public health/medical research, advocating a convergent commitment in media and public health jointly in favour of anti-discrimination legislation related to HIV/AIDS.

Among the earliest analyses of press coverage of HIV in India is of “The Indian Face of AIDS,” an article appearing in *India Today* in 1992, primarily occupied, as Karnik² points out, with assigning risk and blame onto women – specifically sex workers. Coverage of HIV issues following this period employed the same tropes of risk and blame, expanding the scope of risk to upper and middle class citizens^{2,3}, and by recusing “innocent” wives and children of blame, implicitly accusing all other people living with HIV/AIDS (PLWHA, men, sexual minorities, other women) of moral turpitude. In the recent notice in *Mid-Day*, this logic continues to hold: the risk posed by an alleged PLWHA warrants blame and by extension, public disclosure. The conflation of risk and blame is the fulcrum of HIV/AIDS-related stigma^{4,6}, and among the greatest challenges in responding to the epidemic today.

This is not to suggest that there is not great commitment and interest in reducing HIV/AIDS-related stigma: there indubitably is^{5,6}. HIV/AIDS-related stigma and discrimination is on the agenda of almost all HIV/AIDS programmes, especially after the attention placed on the issue by UNAIDS in 2002-3 on the pioneering research showing the high prevalence of stigma among health providers in Maharashtra⁷. Apart from the programmes of various national and international NGOs all over the country, studies and interventions focusing on HIV/AIDS-related stigma have also been undertaken with various populations⁸⁻¹⁰. Between 2004 and 2007, an extensive media training effort of print, radio, and television journalists was undertaken under the auspices of the European Union (EU)¹¹.

Yet, not even three years later, this public notice appeared in a Saturday issue of a fairly widely circulating newspaper alleging an individual to have HIV, adding that “Public are hereby notified to take this aspect into consideration”. The names and addresses of both the notifying and noted individual were provided, along with the parents’ names of the latter. No additional information justifying public consideration of such alleged facts was given, either by the notifier or the editorial staff. The publication of a public notice – and the lack of editorial redress despite public outrage – demands recourse.

Rather than prescribing additional safeguards or study, I propose a closer examination of ethical principles in journalism and in public health that apply specifically to this notice. Their overlap suggests the feasibility of building ethical solidarity across journalism and public health as a way forward in combating the stigma associated with HIV/AIDS that draws upon already agreed upon norms of conduct.

In the domain of journalism, the Press Council of India (PCI) has issued Norms of Conduct, most recently in 2005¹². It explicitly states under Item 36, Clause 5, “Newspapers should not publish an advertisement containing anything which is unlawful or illegal, or is contrary to public decency, good taste or to journalistic ethics or propriety”. It also mentions, according to Item 3, Clauses 1 and 2:

(i) Newspaper should not publish anything which is manifestly defamatory or libellous against any individual/organisation unless after due care and verification, there is sufficient reason/evidence to believe that it is true and its publication will be for public good.

(ii) Truth is no defence for publishing derogatory, scurrilous and defamatory material against a private citizen where no public interest is involved.

According to Item 6, Clause I, “The Press shall not intrude or invade the privacy of an individual, unless outweighed by genuine overriding public interest.” Clarification is provided: “Things concerning a person’s home, family, religion, health, sexuality, personal life and private affairs are covered by the concept of PRIVACY excepting where any of these impinges upon the public or public interest.” Revisions introduced in 1993 make explicit references to HIV and to stigma: “Media must as a role [sic.] respect the right to privacy of AIDS patients and must not subject them to needless exposure and social stigma.” Finally, according to Item 36, Clause 7, “An editor shall be responsible for all matters, including advertisements published in the newspaper.”

In the domain of public health, ethical principles are enshrined in the Ethical Guidelines for Biomedical Research on Human Participants promulgated by the Indian Council of Medical Research (ICMR)¹³. Salient principles include that of precaution and risk minimization where “due care and caution is taken...to ensure that the research participant and those affected by it including community are put to the minimum risk, suffer from no known irreversible adverse effects, and generally benefit ...” The Guidelines also emphasize privacy and confidentiality, explicitly highlighting stigma:

“the identity and records of the human subjects of the research or experiment are as far as possible kept confidential; and that no details about identity of said human subjects, which would result in the disclosure of their identity, are disclosed without valid scientific and

legal reasons which may be essential for the purposes of therapeutics or other interventions, without the specific consent in writing of the human subject concerned, or someone authorised on their behalf; and after ensuring that the said human subject does not suffer from any form of hardship, discrimination or stigmatisation as a consequence of having participated in the research or experiment”.

Finally, the ICMR advocates the principle of totality, “whereby the professional and moral responsibility, for the due observance of all the principles, guidelines or prescriptions laid down generally or in respect of the research or experiment in question, devolves on all those directly or indirectly connected with the research or experiment including the researchers, those responsible for funding or contributing to the funding of the research, the institution or institutions where the research is conducted and the various persons, groups or undertakings who sponsor, use or derive benefit from the research, market the product (if any) or prescribe its use”.

The Table indicates the overlap in these principles. In both the disciplines of journalism and public health, norms exist against harming private citizens, invading their privacy, exposing them to stigma. The accountability for such violations lies with the practitioners of each discipline (editors for journalism, and researchers/ funders/ sponsors for public health). Each institution has its mechanisms of censure (for journalism) and monitoring (for public health). In extreme cases like this, however, an adequate response requires more: it requires punishment.

To this end, ethical principles can be instantiated and enforced in law. In India, such efforts have been underway since 2006. Civil society groups have been trying to introduce an HIV/AIDS bill¹⁴ in Parliament that would adjudicate up to two years of imprisonment for “words whether spoken or written, or by visible representation spreading feelings of hatred against any protected persons,” disseminated in publication, broadcast or advertisement¹⁵. This legislation directly addresses harm, violations of privacy, and stigma mitigation, with specific punishment for those responsible for “spreading feelings of hatred”.

The bill also has media-training components, which will strongly affect popular awareness of the rights of PLWHA and facilitate implementation of the bill’s provisions. While there are debates around amendments introduced by the Law Ministry, there is

Table. Ethical principles in journalism and public health

Principles	Ethical norms of Journalism (PCI) ¹²	Ethical Guidelines of Medical Research (ICMR) ¹³
Harm	“should not publish anything which is manifestly defamatory or libellous against any individual/organisation ... Truth is no defence for publishing derogatory, scurrilous and defamatory material against a private citizen”	“ensure that the research participant and those affected by it including community are put to the minimum risk, suffer from no known irreversible adverse effects, and generally benefit”
Privacy	“shall not intrude or invade the privacy [a person’s home, family, religion, health, sexuality, personal life and private affairs] of an individual, unless outweighed by genuine overriding public interest”	“the identity and records of the human subjects of the research or experiment are as far as possible kept confidential”
Stigma	“respect the right to privacy of AIDS patients and must not subject them to needless exposure and social stigma”	“ensuring that the said human subject does not suffer from any form of hardship, discrimination or stigmatisation as a consequence of having participated in the research or experiment”
Accountability	“An editor shall be responsible for all matters, including advertisements published in the newspaper”	“the professional and moral responsibility, for the due observance of all the principles, guidelines or prescriptions laid down generally or in respect of the research or experiment in question, devolves on all those directly or indirectly connected with the research”

convergence around the urgent need to get this bill into Parliament soon. In support of this move, increasing discussion, awareness, and advocacy related to this bill is the shared responsibility of ethical public health researchers and journalists.

In broader terms, as someone who has been humbled by this incident, it is time for medical and public health researchers to re-invigorate our work around HIV/AIDS, offering support not just to service provision and clinical research, but inter-sectoral solidarity movements for the rights of PLWHA based on shared ethical principles. In addition to members of the AIDS-INDIA listserv that immediately brought this news to our attention, I applaud Outlook magazine and the Hindustan Times (of whom, the latter publication has been part of the EU-Media Training Initiative) for their coverage of these developments, which suggests that the media can be partners in the project of politicizing our work, and certainly, that the foundations for building greater solidarity to combat HIV/AIDS-related stigma and discrimination already exist.

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