Hype and the HIV cure

Some media reports exaggerated the significance of the recent case of a functional cure of a baby with HIV, but that’s a result of publicising unpublished, non-peer reviewed research, says Margaret McCartney

Atul Gawande, the surgeon and author, was one of the first to react. “This is huge, stunning, world changing,” he tweeted, linking to a story of a “startling development” in the New York Times titled “In medical first, a baby with HIV is deemed cured.” The article explained how a baby in the United States had been treated with antiretrovirals 30 hours after birth, and by 18 months of age the baby had no detectable viral load. The New York Times article explained that this demonstrated “proof of principle . . . if we can replicate this case.”

It also reported that other experts would need “convincing that the baby had truly been infected” and that this may have been a case of prevention of transmission rather than cure, as the BMJ also pointed out. It described this development in the context of other knowledge, such as the now established prophylactic treatment of babies born to infected mothers, and it called on seven experts in the article for their views, two of whom were coauthors of the original paper. Although the article acknowledged potential for excitement, it was also clear that deep uncertainty existed.

The same couldn’t be said for much of the UK media. Paper 68LB from the 20th Conference on Retroviruses and Opportunistic Infections, titled “Functional HIV cure after very early ART of an infected infant,” was presented in Atlanta at 10 am on 4 March 2013. However, the press release was issued on 3 March, the same day the New York Times ran its report, before the abstract had been presented. The press release made it clear that researchers would “continue to follow the case” and that they thought that “further research is needed to understand whether the experience of the child can be replicated in clinical trials involving other HIV-exposed children.”

The press release also hinted that the case was unusual because the mother had received no antenatal care or antiretrovirals when she gave birth prematurely; additionally, treatment was stopped when the child was 18 months old for “reasons that are unclear.” The press release had the subheading, “Discovery provides clues for potentially eliminating HIV infection in other children.” The uncertainties—the unusual nature of this case and that the findings are yet to be replicated—were not spelt out, but a quotation from one author did say that this was a “promising lead.”

This important nuance seems to have been eroded in several news reports. The Guardian’s headline was “US doctors make history by curing child born with HIV.” It continued, “Doctors in the US have made medical history by effectively curing a child born with HIV . . . the child has a normal life expectancy and is highly unlikely to be infectious to others, doctors believe.” The researcher was described as “stunned” at this “extraordinary” outcome. The story ended with a note that patients should not stop taking antiretrovirals and that preventive treatments for pregnant, HIV positive women were of proved effectiveness. There was no reminder of the unpubished nature of the report and its lack of peer review or the lack of replication.

Sarah Boseley in the same newspaper the next day explained the limitations of the research: “Is this the big one? Have doctors stumbled across the cure for HIV? Unfortunately not. This is progress . . . but the implications for those already infected or even the still significant numbers of babies born with the virus in the developing world are sadly probably slight.”

The Daily Mail, meanwhile, asked, “Have we found a cure for HIV? Child born with virus is now free of infection after ‘miraculous’ treatment,” and commented, “There is no guarantee that the baby will remain disease free, but early signs do look positive.” The Telegraph hosted a video from a press conference in Atlanta, with one of the researchers, Deborah Persaud, saying that the work “sets the stage for a paediatric cure.”

However, the Telegraph also ran another video featuring the HIV researcher John Frater from Oxford University, who explained the research, its limitations and uncertainties, and the need for patients taking antiretrovirals to continue taking them.

Jon Snow, on Channel 4 News, was right to ask straight away, “How sure are you? Has it been peer reviewed? Are you sustainably excited?” Another of the researchers answered that the development had not been published or peer reviewed but that “other researchers need to know.”

Publicising conference presentations can have problems. The abstract had not been peer reviewed and was presented after the press release. The press release did not spell out the inherent uncertainties in the meaning of this case report. It was left to doctors not involved in the case, including many interviewed by the New York Times, and journalists to unpick the details and ask harder questions.

The risks of hype expand when unchecked enthusiasm seeks coverage before publication. Although research should be published without undue delay, generating press coverage is not always useful for the research community, patients, or citizens. Many comparisons in the press were made with the case of the “Berlin patient,” a man with HIV who had a bone marrow transplantation in 2009 and was subsequently found to have been functionally cured of HIV. Yet this has not, so far, been repeated.

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References are in the version on bmj.com.
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