

An attempt to analyze the narrative world of the life-stories of doctors and patients involved in the HIV tainted blood product incident in Japan

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Objectives:

We had conducted the research projects started in 2001 ended 2010, which aimed at collecting and analyzing the life-stories of doctors and patients involved in the HIV tainted blood product incident in Japan in 1980s-90s. The objective of this qualitative research is to give life to the subdued world of narratives of the involved; the media has over-simplified this incident so that the varieties of lived experiences had been left unattended. We attempted to reconstruct the lived life-world of doctors and patients not only from the life-stories narratives but also from re-specifying the related papers then published in the various medical and academic journals. The result of this research would be more objective and unbiased assessment of this incident in Japan.

Methods:

First, we adopted an active interview approach introduced by J. Holstein and J. Gubrium in order to enable the interviewees to become active storytellers; we are aware of the possible reluctance of story-telling on the side of doctors, since they could sometimes feel guilty for this incident, in other times, they could have fear of being blamed. Second, we set up the publicly acknowledged research committee to give our research an objective character and curtail possible distrust against being interviewed. In addition, we established the moral and privacy code of this research; we made transcripts of the interview and toiled at gaining permission of interview excerpts from doctors and patients under strict anonymity.

To interpret the transcript of the interviews, we adopt an sociology of knowledge approach. Not only we collected and examined the related medical journals then published, but we had also done intensive fieldworks of hemophilia clinics and HIV medical care teams so that we could fill in the proper medical and historical context for interpreting the individual transcript.

Results:

We were successful in publishing 30 transcripts of interviews belonging to 13 doctors and 38 transcripts of interviews belonging to HIV positive hemophilia patients and the deceased family members, which together culminated in 2257 pages of 2 volumes as the final report of the research.

Against the simplified bipolar model of the perpetrator and the victim of this incident, we found more complicated and individualized world of life-stories which would reflect the differences of social and historical context where each interviewee was situated at that time. First, the doctors had been thrown into the uncertainty and indecisiveness toward the then unknown disease of HIV infection for a long time, which would result in refraining from taking a clear-cut attitude concerning the use of non-heated concentrated blood product. For most doctors, the change from cryoprecipitate to concentrated product meant undoubtedly a quantum progress of medical care treatment for hemophiliacs; to return to the old method of treatment looked retrogression and might run the risk of engendering the lives of hemophiliacs by the higher rate of intracranial bleeding.

Second, the older generations of hemophilia in Japan unanimously experienced the unbearable painfulness of bleeding and was told by parents that they would die young. For them, the anti-hemophilia factor concentrate was regarded as the miracle medicine to ease the pain and to endow a long life. However, facing up the occurrence of HIV infection, they felt being kept separated from every trustworthy information sources.

Conclusions:

Although, the frank communication between doctors and patients should be acutely demanded at the time of confusion and uncertainty, we found little evidence of any interchange between them. Some patients' deep distrust to the doctors might be traced back to this lack of communication. However, some patients could continue to trust the doctors and did not feel abandoned by doctors. In these cases, after the doctors were aware that they had infected their patients with HIV, they decided to start studying the medical treatment for HIV infection and continue to care for their old hemophilia patients. The doctors' new enterprise for HIV treatment could be interpreted as one expression of taking the responsibility for infecting their patients with HIV.

References:

The research committee of the problem of HIV infection caused by the imported blood product in Japan, 2009, The final report of the sociological research on the issues caused by HIV tainted blood product imported in 1980s from U.S. to Japan; An life-story narrative approach to the people involved in this incidents in Japan. Vol.1-Vol.3. NPO MERS; Medical Care and Human Rights Network, Osaka, Japan.
J. Holstein & J. Gubrium, 1995, The Active Interview, Sage Publications

