

ORIGINAL

Tokyo

AIDS AND THE SOCIAL ORDER

BY

C. EVERETT KOOP, MD, ScD

SURGEON GENERAL

OF THE

U. S. PUBLIC HEALTH SERVICE

U. S. DEPARTMENT OF HEALTH AND HUMAN SERVICES



PRESENTED TO THE WHO/JAPAN JOINT CONFERENCE  
ON AN INTEGRATED STRATEGY FOR THE  
CONTROL OF AIDS AND OTHER HUMAN RETROVIRAL INFECTIONS  
AND HEPATITIS B  
TOKYO, JAPAN  
OCTOBER 6, 1987

(GREETINGS TO HOSTS, GUESTS, FRIENDS, ETC.)

I APPRECIATE THIS OPPORTUNITY TO ADDRESS THIS DISTINGUISHED GROUP OF SCIENTISTS. I ALSO WANT TO THANK OUR HOSTS FOR OPENING UP THE TOPIC OF INFECTIOUS DISEASES SO THAT WE CAN LOOK AT THE SOCIAL, ECONOMIC, AND CULTURAL EFFECTS OF THE EPIDEMIC OF AIDS.

I WANT TO SPEND A FEW MOMENTS REVIEWING FOR YOU -- ALBEIT IN A BRIEF MANNER -- SOME OF THE DIFFICULT CHOICES THAT LIE AHEAD OF US, RELTAIVE TO THE PANDEMIC OF AIDS.

FIRST, LET ME REMIND YOU THAT THE THREE ASPECTS OF AIDS THAT COLOR EVERYTHING DONE AND SAID ABOUT THE DISEASE ARE, ONE, THAT IT IS STILL A MYSTERY...TWO, THAT IT IS FATAL...AND THREE, THAT PEOPLE GET AIDS BY DOING THINGS THAT THE MAJORITY OF PEOPLE DON'T DO AND DON'T LIKE.

WE NEED TO KEEP THESE THREE ASPECTS OF THE DISEASE IN MIND, BECAUSE THEY, IN COMBINATION, TRULY OBSCURE THE MANY SCIENTIFIC ISSUES SURROUNDING AIDS AND, INSTEAD, SWING OUR ATTENTION TO THE MORE VOLATILE ISSUES OF LAW, ETHICS, ECONOMICS, MORALITY, AND SOCIAL COHESION THAT SURROUND AIDS.

WE CAN SEE THIS MOST CLEARLY IN THE WAY THE EPIDEMIC OF AIDS HAS AFFECTED THE WORLDWIDE SYSTEM OF MEDICAL INTELLIGENCE ITSELF, WHICH HAS BEEN A MAJOR ADVANCE FOR THE CAUSE OF PUBLIC HEALTH.

THE PRESENCE OF AIDS IN THEIR MIDST IS A PROFOUND EMBARRASSMENT -- TO SAY THE LEAST -- FOR MANY NATIONS OF THE WORLD.

WORSE, ITS PRESENCE CAN BE AN AFFRONT TO THE MORAL STANDARDS OF MANY SOCIETIES. AND I SUSPECT THAT SOME OF THESE HAVE CHOSEN TO MAKE THE DISEASE DISAPPEAR BY SIMPLY NOT PUBLICLY REPORTING ITS PREVALENCE.

LET ME HASTEN TO ADD THAT THIS IS NOT A PROBLEM PECULIAR TO THE THIRD WORLD. IT IS A PROBLEM WE ALL FACE TO A CERTAIN DEGREE.

EVEN IN MY COUNTRY, WHICH I THINK HAS BEEN VERY CANDID ABOUT THE PREVALENCE OF AIDS, WE MUST CONTINUE TO PROVIDE ENCOURAGEMENT AND SUPPORT TO THE TOTAL EPIDEMIOLOGICAL EFFORT, BEGINNING WITH THE INDIVIDUAL HEALTH WORKERS WHO ARE ON THE FRONT-LINE OF DATA COLLECTION. THESE ARE THE PEOPLE WHO MUST BE PROFESSIONALLY COMMITTED TO MAINTAINING THE INTEGRITY OF HEALTH DATA. THEY MUST NOT COMPROMISE THAT DATA FOR ANY REASON.

YES, HEALTH DATA CAN, TO SOME DEGREE, CONTRADICT A NATION'S POLITICAL, ECONOMIC, SOCIAL, OR CULTURAL LIFE. SMALL-POX DATA DID THAT AND MALARIA AND TUBERCULOSIS DATA STILL DO.

BUT AIDS DATA ARE HAVING THIS EFFECT TO A VERY MARKED DEGREE. I UNDERSTAND WHY THE POLITICAL AND PUBLIC HEALTH LEADERS IN SOME COUNTRIES DO NOT WANT TO COLLECT AND PUBLISH SUCH DATA. BUT I URGE THEM TO RELENT, SINCE WE CANNOT TRULY UNDERSTAND A DISEASE, MUCH LESS STOP IT, IF WE DON'T KNOW WHERE IT IS AND HOW IT IS ACTING.

YOU CAN'T QUANTIFY THESE THINGS, BUT I AM NEVERTHELESS PERSUADED THAT THE UNDER-REPORTING OF THE PREVALENCE OF AIDS IS A FACTOR RETARDING OUR PROGRESS IN THE FIGHT AGAINST THIS DISEASE.

AS OF LATE LAST MONTH, W.H.O. REPORTED THE TOTAL AIDS CASE-LOAD IN COUNTRIES OTHER THAN THE UNITED STATES TO BE 14,600, A FIGURE THAT SEEMS TO BE WELL BELOW WHAT WE MIGHT HAVE EXPECTED.

AND INDEED, SOME COUNTRIES HAVE REPORTED 1 CASE OR NO CASES AT ALL, WHILE OTHER COUNTRIES -- SOME SHARING COMMON BORDERS -- REPORT SEVERAL HUNDRED...OR A THOUSAND OR MORE.

THE DISEASE IS NOT SLOWING DOWN. ALL TOTALS ARE GETTING LARGER. AND THEREFORE IT IS CRITICAL THAT EVERY NATION REPORT AS FULLY AND AS ACCURATELY AS POSSIBLE THE EXTENT TO WHICH THE DISEASE IS PRESENT WITHIN ITS BORDERS -- DESPITE THE DISCOMFORT THIS MAY CAUSE FOR THE CITIZENS AND THE POLITICAL AND PUBLIC HEALTH LEADERS OF EACH NATION.

THE DISEASE OF AIDS IS ALSO TESTING THE DEGREE TO WHICH HEALTH WORKERS -- PHYSICIANS, NURSES, TECHNICIANS, AND OTHERS -- UNDERSTAND AND ARE TRULY DEDICATED TO THE ETHICAL FOUNDATION OF HEALTH CARE ITSELF.

WE ARE HEARING EVERY DAY SOME STORY OR OTHER INVOLVING A HEALTH PROFESSIONAL -- OR A GROUP OF PROFESSIONALS -- WHO REFUSE TO TREAT PERSONS WITH AIDS...OR EVEN TO TREAT PERSONS WHOM THEY SUSPECT OF HAVING AIDS.

I DO NOT FOR A MOMENT BELIEVE THAT THIS IS THE CHARACTERISTIC BEHAVIOR OF HEALTH PROFESSIONALS. THE OVERWHELMING MAJORITY OF OUR COLLEAGUES HAVE PROVIDED -- AND WILL CERTAINLY CONTINUE TO PROVIDE -- QUALITY, COMPASSIONATE CARE TO PERSONS DYING OF AIDS WHEREVER THEY ARE.

BUT THE GOOD CONDUCT OF THE MAJORITY SHOULD NOT IN ANY WAY SHIELD THE POOR CONDUCT OF A FEARFUL AND IRRATIONAL MINORITY.

I MUST REMIND YOU, HOWEVER, THAT THE RECORD OF THE SEVERAL HEALTH PROFESSIONS IS NOT VERY GOOD ON THIS MATTER OF HOLDING COLLEAGUES TO A CLEAR STANDARD OF ETHICAL CONDUCT. I DON'T THINK THAT'S A PROBLEM UNIQUE TO ANY ONE COUNTRY EITHER. IT'S ONE THAT, UNFORTUNATELY, EVERY ONE OF US MUST STRUGGLE WITH.

NOR WILL I SAY THAT THE PROBLEM REGARDING AIDS PATIENTS IS MORE SERIOUS THAN ANY OTHER. THAT'S NOT TRUE BECAUSE WHENEVER A HEALTH PROFESSIONAL COMPROMISES THE ETHICS OF THE HEALING ART -- INVOLVING WHATEVER DISEASE OR CONDITION -- IT IS A SERIOUS MATTER.



BUT THE DENIAL OF SERVICES TO PEOPLE WITH AIDS IS ESPECIALLY SIGNIFICANT BECAUSE OF THE OFTEN PROTRACTED AND EXTREMELY DEBILITATING NATURE OF THE AIDS-RELATED TERMINAL ILLNESSES. THESE ARE ILLNESSES WHICH ARE LABOR-INTENSIVE. IN OTHER WORDS, WE NEED ALL THE COMMITMENT OF ALL THE HEALTH PROFESSIONS TO GET US THROUGH THE NEXT DECADE OR SO, AS THE DISEASE PROGRESSES.

IT IS ALSO ESSENTIAL THAT PHYSICIANS, DENTISTS, NURSES, AND OTHERS ESTABLISH A DE MINIMIS LEVEL OF RATIONALITY THAT THE REST OF SOCIETY CAN FOLLOW, RELATIVE TO OUR CONDUCT TOWARD THE CLASSES OF PEOPLE AMONG WHOM THE DISEASE SEEMS TO BE MAKING THE MOST HEADWAY.

AS WE IN MEDICINE KNOW FULL WELL, THE DISEASE OF AIDS IS NOT INTRINSIC TO HOMOSEXUALITY, AS IT NOT INTRINSIC TO HETEROSEXUALITY. YET, THAT DISTINCTION IS LOST ON SOME PEOPLE, WITH THE RESULT THAT WE ARE SEEING -- IN OUR COUNTRY AND ELSEWHERE IN THE WORLD -- A RISE IN HOMOPHOBIA, THAT IS, THE HATRED OF -- AND VIOLENCE AGAINST -- HOMOSEXUALS AND BISEXUAL MEN.

HEALTH PROFESSIONALS MUST NOT IN ANY WAY CONTRIBUTE TO SUCH IRRATIONAL BEHAVIOR. AND DENYING HEALTH SERVICES TO HOMOSEXUALS OR BISEXUAL MEN -- WHETHER THEY HAVE AIDS OR NOT -- IS ALSO IRRATIONAL AND CANNOT BE EXCUSED OR CONDONED.

AS A PHYSICIAN, I AM PROUD TO BE PART OF A TRADITION OF CARE THAT GOES BACK MORE THAN TWO MILLENIA...A TRADITION THAT WILL NOT ABANDON THE SICK AND THE DISABLED...WHOEVER THEY ARE.

HENCE, I REGARD AS EXTREMELY SERIOUS THE REPORTS OF A FEW PHYSICIANS AND OTHERS WHO ARE WITHHOLDING CARE FROM PERSONS WITH AIDS OR PERSONS OF A PARTICULAR GROUP WHO NEVERTHELESS DO NOT HAVE AIDS. THAT KIND OF CONDUCT THREATENS THE VERY FABRIC OF HEALTH CARE EVERYWHERE IN THE WORLD.

I BELIEVE WE MUST ALL CONFRONT THIS ISSUE AND COME FORWARD WITH SOME ANSWERS. OTHERWISE THE VIRUS OF AIDS WILL FURTHER WEAKEN THE ETHICS OF MEDICAL PRACTICE IN EVERYONE OF OUR HOME COUNTRIES. AND THAT WOULD BE ANOTHER AND JUST AS DEADLY AN EPIDEMIC FOR OUR THE HUMAN RACE.

A RELATED ISSUE CONCERNS THE COST OF CARE FOR AIDS PATIENTS:  
WHAT MIGHT THOSE COSTS BE? AND WHO SHOULD PAY THEM?

AS YOU KNOW, WE HAVE A MIXED SYSTEM OF SUPPORT FOR HEALTH CARE  
IN THIS COUNTRY: PRIVATE METHODS OF PAYMENT EXIST SIDE-BY-SIDE WITH  
PUBLICLY SUPPORTED SYSTEMS OF REIMBURSEMENT FOR CARE.

AT THIS POINT THE TOTAL ANNUAL EXPENDITURE FOR THE MEDICAL CARE  
OF AIDS PATIENTS IS ABOUT \$1.6 BILLION. HOWEVER, OF THAT TOTAL, THE  
AMERICAN TAXPAYER CONTRIBUTES ABOUT 1 DOLLAR OF EVERY 4, OR  
SOMETHING ON THE ORDER OF \$400 MILLION THIS YEAR.

OF COURSE, THE AMERICAN TAXPAYER SUPPORTS A GREAT RANGE OF PUBLIC HEALTH PROGRAMS. MOST OF THEM EITHER HELP PROMOTE OR MAINTAIN AN INDIVIDUAL'S GOOD HEALTH, OR THEY HELP RETURN THE INDIVIDUAL TO A STATE OF GOOD HEALTH.

BUT AIDS IS DIFFERENT.

IT'S VERY EXPENSIVE...WELL OVER \$600 A DAY ON THE AVERAGE FOR IN-PATIENT CARE. BUT THEN, AFTER CONSUMING TENS OF THOUSANDS OF DOLLARS WORTH OF MEDICAL CARE AND SOCIAL SERVICES...THE AIDS PATIENT DIES.

WE ANTICIPATE THAT, OVER THE NEXT FOUR YEARS, THE ANNUAL AIDS CASE-LOAD WILL MORE THAN DOUBLE AND THE ANNUAL COST OF CARE WILL MORE THAN TRIPLE.

WILL THE AMERICAN PEOPLE CONTINUE TO SUPPORT HIGH-COST PATIENT CARE FOR PEOPLE WITH AIDS? OR WILL THEY ASK FOR RELIEF? AND IF THEY DO, WHAT WILL THAT DO TO THE ACCESSIBILITY OF MEDICAL CARE...OR THE QUALITY OF MEDICAL CARE...FOR AIDS PATIENTS IN OUR COUNTRY?

I'D LIKE TO THINK THAT THE AMERICAN TAXPAYER WILL DO THE RIGHT THING AND CONTINUE TO SUPPORT QUALITY, ACCESSIBLE CARE FOR ALL AIDS PATIENTS. BUT I DON'T KNOW.

AND WHAT ABOUT MEDICAL CARE IN COUNTRIES NOT AS FORTUNATE AS OURS? HOW WILL THEY RESPOND TO THE PRESSURE FOR MORE AND MORE RESOURCES FOR THE MEDICAL CARE OF TERMINALLY ILL PATIENTS...PATIENTS WHO BECAME ILL, REMEMBER, BECAUSE THEY PROBABLY DID SOMETHING THEY OUGHT NOT TO HAVE DONE?

I CAN'T ANSWER THAT AT ALL. AND I WONDER WHO AT THIS MEETING CAN?

THEN THERE IS THE ISSUE OF INDIVIDUAL PRIVACY VERSUS THE NEED TO PROTECT THE COMMUNITY FROM DANGER. THIS ISSUE WAS TRIGGERED IN 1985 BY THE AVAILABILITY OF A RELIABLE BLOOD TEST FOR AIDS AND THE CONSEQUENT NEED TO DECIDE ON THE CONFIDENTIALITY OF THE BLOOD TEST RESULTS.

I DON'T BELIEVE EITHER SIDE OF THIS QUESTION REQUIRES AN ABSOLUTE RESPONSE, BUT HOW MUCH LEEWAY DO WE REALLY HAVE?

THIS ISSUE, I'M AFRAID, IS TIED DIRECTLY TO THE WAY EACH SOCIETY DEFINES ITS COMMITMENT TO INDIVIDUAL LIBERTY. THE MORE FREE THE SOCIETY, THE MORE CONCERN THERE IS FOR THE INDIVIDUAL'S RIGHT TO PRIVACY. THE LESS FREE, THE LESS CONCERN FOR THIS RIGHT.

CONVERSELY, IN THOSE SOCIETIES JUST EMERGING FROM COLONIALISM AND TRYING TO FOLLOW THEIR OWN PATHWAYS TO A FREE AND DEMOCRATIC FUTURE, THE PROTECTIVE DECISION BY A FEARFUL SOCIETY TO PROTECT ITSELF FROM THE INFECTED INDIVIDUALS IN ITS MIDST MAY, BY ITSELF, DO MORE TO DEFINE THE NATURE OF THAT SOCIETY THAN ANY OTHER EFFORT OR ACTIVITY.



HOW TRAGIC IT WOULD BE, IF MANY OF THE EMERGING NATIONS OF AFRICA AND ASIA DECIDE TO LIMIT THE RIGHTS OF INFECTED INDIVIDUALS, IN ORDER TO GIVE SOCIETY AT LARGE A GREATER SENSE OF SECURITY.

FINALLY, AND PROBABLY MOST IMPORTANT OF ALL FOR AMERICANS, WE SEE MORE EVIDENCE EVERY DAY THAT THIS DISEASE IS BECOMING THE PARTICULAR SCOURGE OF PEOPLE WHO ARE YOUNG, BLACK, AND HISPANIC.

HOW TRAGIC FOR THEM.

AND HOW TRAGIC FOR ALL OF US.

IN VIRTUALLY EVERY EPIDEMIC OR PLAGUE IN HUMAN HISTORY, SOCIETY HAS FOUND A CONVENIENT SCAPEGOAT. THE SCAPEGOAT IS USUALLY POOR, A MINORITY OF SOME KIND -- RACIAL, RELIGIOUS, OR ETHNIC -- AND TOO WEAK TO FIGHT BACK.

DURING THOSE PERIODS OF THE GREAT EPIDEMICS, THE MAJORITY GAINED A FEELING OF SECURITY AND SATISFACTION, IF IT COULD SOMEHOW PUNISH A WEAKER AND VERY VISIBLE MINORITY BY OSTRACISM, QUARANTINE, OR THE DENIAL OF BASIC HUMAN RIGHTS.

THE MARK OF MATURITY OF A PEOPLE, OF COURSE, IS THE DEGREE TO WHICH THEY REJECT THIS KIND OF BEHAVIOR. AND I AM PROUD OF THE WAY THE UNITED STATES HAS TACKLED THE ISSUE OF FAIRNESS TO ITS MINORITIES.

WILL THE DISEASE OF AIDS -- ALL BY ITSELF -- REVERSE THIS TREND IN RECENT HUMAN HISTORY? WE HOPE AND PRAY THAT IT WILL NOT.

BUT HOPES AND PRAYERS MAY NOT BE ENOUGH. WE WILL NEED COURAGEOUS LEADERSHIP AT ALL LEVELS OF GOVERNMENT AND THROUGHOUT ALL SOCIAL AND POLITICAL INSTITUTIONS TO REINFORCE THOSE HOPES AND PRAYERS.

YES, IT IS TRUE THAT THE GREAT MAJORITY OF AIDS PATIENTS SO FAR HAVE BEEN HOMOSEXUALS, DRUG ADDICTS, BLACKS, AND HISPANICS. ABOUT 38,000 OF THEM.

AND IN OTHER COUNTRIES THE PEOPLE WITH AIDS HAVE BEEN DRAWN FROM THESE AND OTHER MINORITY GROUPS.

SO WE MUST ASK IF WE ARE TRULY MATURE ENOUGH TO BE COLOR-BLIND IN THIS WAR AGAINST AIDS? AND CAN WE OVERLOOK THE SOCIAL STATUS OF THE INDIVIDUAL WITH AIDS?

ARE WE SECURE ENOUGH TO EXTEND OUR VERY BEST MEDICAL CARE EVEN TO THE VERY LEAST OF OUR CITIZENS?

THESE AND OTHER QUESTIONS LIE ON THE HORIZON BEFORE US. BUT THE HORIZON IS NOT THAT FAR AWAY.

I HOPE WE WILL NOT STUMBLE TOWARD IT AND ARRIVE UNPREPARED FOR THE CHALLENGES THAT LIE BEYOND.

I HOPE THAT, INSTEAD, WE WILL MOVE FORWARD WITH GOOD SENSE AND GOOD SCIENCE AND, TOGETHER, GIVE THE WORLD SOMETHING EVERY BIT AS PRECIOUS AS THE MUCH-DESIRED AIDS VACCINE; WE WILL SHOW THE WORLD HOW COMPASSION AND JUSTICE CAN TRIUMPH OVER DISEASE.

ONCE AGAIN...THANK YOU.

# # # # #