QUANTIFIABLE HEALTH AND SOCIAL WELL BEING: COMPETING CONCEPTS

I start out from the premise that the idea of health is not self-evident; on the contrary, it is a concept the meaning of which changes through time and space. The assumption that health is quantifiable; a condition signified by the absence of known diseases or in terms of longevity and, moreover, its preservation is primarily the responsibility of individuals is a product of the social times in which we live. Inevitably, social, cultural, and political meanings are implicated in how health is conceptualized, and confining attention largely to the condition of de-contextualized individual bodies\(^1\) brings with it a cluster of moral and political consequences that I will elaborate on below in three case studies.

Historical and anthropological research has shown that all human groups have a shared concept of what constitutes a well functioning social, political, and moral order, one that is intimately associated with the physical health and well being of individuals who constitute the group (see, for example, Janzen:1981; Lock:1980). Such values are not static, of course, nor are they shared equally among people who live together in complex societies; very often these concepts are highly politicized and actively disputed. At the present time disputes frequently center on explicit opposition to what is seen as an infiltration of “western ideas” with an emphasis on individual rights and autonomy that threaten “traditional” moral order (Ferzacca:2002; Pigg:2002).

In this paper, rather than focusing on discourse that is openly political, I want to take a somewhat different trajectory and examine several of the assumptions associated with biomedicine and public health practices as they are applied globally. My position is that unless a critically reflective approach is incorporated into global health research and

\(^1\) Public health is of course a partial exception to this assertion.
its application, the ultimate objective of improving the well being of populations worldwide has little chance of success.

A. Infertility – “A blessing in disguise”?

In contrast to the “developed” world, infertility is endemic in Central and Southern Africa and very high elsewhere on the continent. It is of note that the causes of infertility and its management are strikingly different in the North and the South. Sexually transmitted diseases (STDs), usually readily treatable by antibiotics, are not the cause of most cases of infertility in the North. For the majority of cases IVF clinics enable people who desperately want children to achieve their desire, provided they have the financial resources. The situation is entirely different in Central and Southern Africa. Although worldwide it is estimated that between 8 and 12% of couples are unable to reproduce at some point in their lives, in the “infertility belt” of Central and Southern Africa, as many as one third of all couples may be affected (Inhorn:1994; Inhorn and van Balen:2002). By far the majority of these cases are due to STD’s and are, therefore, treatable – a situation that was recognized as early as the 1970s. Further, it is believed that over half of these cases are due to male infertility but, because locally infertility is regarded almost without exception as a “woman’s problem,” it is the women whose lives are more often than not destroyed as a result of the situation.

I well remember when I carried out several months of fieldwork among the Samburu of eastern Kenya the sorry state of women who had been labeled as “barren.” Thrown out by their husbands, these women could not return to their natal families and had no choice but to become prostitutes in the nearest shantytown. Of course, co-wives in this polygynous society soon recognize that the problem may well be that of their husband and not due to their own shortcomings; they quickly remedy the situation through a clandestine meeting with a handsome young warrior. But the first woman to become a man’s wife is vulnerable and, above all, those women who are indeed infertile are exceptionally vulnerable.

Despite exceptionally high rates of infertility, overall fertility levels remain high in Central and Southern Africa -- and the goal of the “fertility transition” set out by the United Nations has not been met. Among health care practitioners and policy makers,
particularly those who are expatriates, the idea that infertility should be regarded as a problem is usually met with disdain. Marcia Inhorn notes that policy makers in these countries are often obsessed with curbing population growth, and essentially ignore large subpopulations where the rule is one of “barrenness amidst plenty” (Inhorn:1996). When Karina Kielmann undertook an ethnographic study of infertility in Zanzibar in the 1990s the resident Irish midwife with whom she spoke thought Kielmann was wasting her time, and described infertility as a “blessing in disguise.” However, in reality the tragedy is such that efforts to overcome infertility have been a key part of indigenous medical systems everywhere from time immemorial.

As is well known, for the past thirty years at least, in Africa the interest of health policy makers has been primarily concerned with population reduction. The prevailing image is one of excessive fertility that must be controlled. Family planning services are very visible but Kielmann found that in Zanzibar, as is the case in the majority of other African countries, these services are artificially separated from facilities that provide control of and cures for STDs. Kielmann notes that STD clinics are severely underfunded and tend to be highly stigmatized by local populations, with the result that infertility persists as a partially hidden problem for which many women receive no care at all. It was clear to Kielmann that expatriate health workers made little effort to understand local idioms of distress used by women to describe the shaming condition of infertility, although the signs of secondary infertility -- pelvic inflammatory disease and spontaneous abortions -- are undeniable. Even so, she found that practitioners are reluctant to assign their meager medical resources to treat either primary or secondary infertility. The result is that women visit traditional healers, and then very often quickly return once again to the local biomedical clinic in their desperate search for help, sometimes actively encouraged to do so by local healers (Kielmann:1993).

The Danish researcher Lisa Ann Richey has recently carried out research in connection with reproductive health in Tanzania. She points out that since 1994 in Tanzania national public expenditure for reproductive health has steadily declined, and what funds remain available have been devoted almost exclusively to clinics handing out contraceptives. This decline has taken place in spite of a general agreement arrived at in 1994 at the Cairo International conference on Population and Development stating that
emphasis should be given to the overall improvement of women’s reproductive health as a key goal in strategies for economic development. Richey argues convincingly that, commencing in 1995, the Tanzanian government came under stringent pressures to carry out “structural adjustment” by Tanzania’s donors and lenders, integral to which was a demand to bring about fertility decline as rapidly as possible, with a narrow focus on birth control rather than more generally on reproductive health.

Once the economic decline associated with structural adjustment began to take its toll, Tanzanians reported that they were deliberately reducing the size of their families because of increasing poverty, with the result that the total fertility rate dropped quite significantly. The new Tanzanian National Family Planning Program was heralded as a success by outside observers. However, on the basis of fieldwork in the Kiliamajaro region, Richey readily observed that medical services were abysmal and the health of both men and women was in decline. Health workers complained to Richey about a chronic shortage of even the most basic supplies including sterile gloves, syringes, gauze, and so on. They could not insert IUDs but, even more important, they had no access to antibiotics because this type of medication is not considered of any use in family planning clinics. Infections go untreated, therefore; as a result doctors documented that from the mid 1990s infertility rose quite dramatically, as did high risk births. They also noted that, rather than coming to the family planning clinics, people preferred to treat themselves with bush medicine. Richey points out that Tanzanian women had more access to reproductive health care in the 1970s than they do at the present time. Today, 35–45% of all deaths in adult women are due to HIV/AIDS, but integration of care for HIV into the Family Planning Program has not even started, with the result that the majority of women have nowhere to turn when they attempt to avoid or combat this disease.

Richey is scathingly critical of top-down donor-reliant initiatives that push contraception alone in preference to providing reproductive health care. The Tanzanian government has steadily withdrawn funding from the health care sector, with the exception only of those clinics that provide family planning, even so their approach is praised internationally as a model for other countries. For example, the former British Secretary of State for International Development is on record as stating: …Tanzania’s
achievements in economic reform and improvements in health and education are very impressive (2002). And yet Richey found that nearly half of the residents in one of Tanzania’s wealthiest rural areas have no access to formal health care at all.

Because policy makers assume that Africa is in a chronic state of emergency as a result of the HIV/AIDS epidemic, reproductive health, including infertility, is given less and less attention. However, the stigma and failure associated with being a “barren woman” remains. This problem is compounded because young married women are strongly encouraged by health care workers never to have unprotected sex and therefore, presumably, never to produce children. And yet children are essential, not simply as a source of pride and for the continuity of the lineage, but for their contribution to the family income and, once older, as the only form of social security for the elderly. My colleague Vinh-Kim Nguyen states that in 2001 and 2002, in the early years of expanded treatment for HIV, the community groups he was working with in West Africa noted that up to 20% of the women receiving treatment “disappeared” once pregnant, for fear of being scolded. This phenomenon has yet to be rigorously studied, but it is clear that, even for young married women with HIV, their duty to contribute to family wellbeing outweighs concerns about their own health.

Adding to the problems, general health care is essentially non-existent, putting the key tasks of women as laborers and money earners in jeopardy should they become sick; and, because with migration to the city access to good nutrition has declined, diabetes rates have soared. Furthermore, the structure of the African family has changed dramatically due to the deadly effects of HIV/AIDS, leaving middle aged and older women as the only source of care and support for young children, even so, their basic health problems go untended.

At present, this situation is perpetuated with no end in sight because developing countries must respond to the global forces of economic restructuring that more often than not bring about local economic decline. When coupled with the “silo-ing” of health care programs – a narrow focus on family planning; targeted reduction in family size, and HIV prevention -- the effects on the physical health of local populations is devastating.

It is tempting to assume that the persistent misdirection of aid cloaks a thinly disguised racism exacerbated by stereotypes about promiscuity with the result that policy
making is dangerously skewed. To fail to treat infertility and other basic medical needs is
to ride roughshod over international guidelines and well-documented findings associated
with success in the fertility transition in other countries. In Africa, as is the case in many
other parts of the world, reproduction is not merely a personal matter. Family security,
health, and wellbeing are inextricably associated with successful reproduction, and to be
infertile is a fate worse than death, even death from HIV/AIDS.

B. Standardization and the Assumption of a Universal Body

A second example illustrates the way in which a narrowly defined
decontextualized focus on the standardization of medical practice with intent to improve
health care outcomes can result in unanticipated consequences. Standardization inevitably
involves the creation of scales and measurements on the basis of which decisions are
made about what will count as normal and abnormal. The process of labor and birth, for
example, has been progressively regulated over the past twenty years so that this
supremely subjective experience is now transformed into a statistically constructed
process whereby the duration of the stages of delivery and the timing of the transitions
from one stage to another must occur within medically established parameters. Almost all
hospital births in Europe and North America today carry out an “active management of
labor” based on what are known as the Friedman Curves. The result of this normalization
of birth is that increased pressure is placed on many women, particularly “white” women,
to “speed up” the birth process. In the Canadian north, in contrast, common knowledge
shared both by Inuit women and health care professionals familiar with that environment
is that “normal” labor among Inuit is remarkably rapid. Inuit women themselves take a
pride in quick deliveries, to which diet and environment may well contribute.

In the early 1980s, in an effort to try to reduce what was perceived erroneously to
be an unacceptably high infant mortality rate, the Canadian government implemented a
policy whereby all Inuit women were to be “evacuated” a month before their due date
and flown south to give birth. This policy caused great distress, not only because women
were isolated from their families, but because they were systematically subjected to
technological interventions in hospitals in the Canadian south, where it became regular
practice to slow down what were designated as abnormal labor experiences to fit with the
management of labor according to the standardized Friedman curves.\(^2\) Enforced isolation in hospitals where people did not speak their language and where the food was indigestible, coupled with efforts to slow down labor, led quickly to active resistance to the evacuation policy on the part of Inuit women, some of whom would disappear into the bush rather than be forcibly placed on an airplane (Kaufert and O’Neill:1990;1993).

In the intervening years, as a result of consultation and negotiation among Inuit, epidemiologists, health care workers, and government officials, several policy modifications have been made, with the result that well-trained midwives, many of them Inuit, work across northern Canada and assist at all deliveries except those deemed to be at high risk. For those women at high risk, giving birth still commences with a flight of over 1000 miles in order that labor may be technologically managed in the tertiary care hospitals of urban Canada (Kaufert and O’Neill:1990).

This example highlights a serious conflict between authoritative and subjective accounts about what constitutes a “normal” birth. The discrepancy arises as the result of an unexamined assumption on the part of the majority of obstetricians that their knowledge can be applied without modification to all births, regardless of significant biological, cultural, social, and economic differences among pregnant women. This assumption persists even though considerable evidence exists to suggest that pregnancy and birth are affected by numerous factors, making uniform standardization highly problematic. The Friedman curves were constructed on the basis of a hypothetical average white body that became the standard around which acceptable variation in the timing of all births is established. Even though the language and practices of biomedicine are in theory rational and free of moralizing, it is clear that what counts as normal and abnormal can be associated with unexamined assumptions about a uniformity of bodily events and conditions that on occasion lead to practices that verge on serious abuse.

Several biological and cultural anthropologists, myself included, have challenged the assumption of a universal body. My argument is not simply a call for recognition of the social and cultural construction of disease and illness; rather, the position I take is one in which biological difference and its profound interdependence with historical,

\(^2\) There is some evidence to indicate that the bodies of Inuit women have been biologically selected for rapid labor and delivery.
environmental, social and cultural variables is acknowledged (Lock:1993). Recently, genomic research has made it clear that the small amount of genetic variation that exists among human populations can be highly significant with respect to risk for specific conditions. These findings are not limited to the rare, single gene disorders associated with specific ethnic groups, but extend to significant differences in incidence in connection with complex diseases including cancer, diabetes, obesity, dementia, and so on. Investigation of the interaction of susceptibility genes (that play a part in disease causation, but by no means determine it) with social and environmental variables (so far rather poorly understood) is beginning to challenge both the dogma of genetic determinism that has dominated genetic research for the past 60 years and, at the same time, force a recognition of the importance of epigenetic variables in disease causation. These findings raise a strong cautionary note for global health endeavors because many of the disease taxonomies routinely used in biomedicine are now undergoing interrogation and may well be broken down into smaller sub-taxonomies some of which will be associated with specific geographical and environmental locations making for complexities in both diagnosis and treatment. The absolute numbers of people suffering from complex diseases are greater in the “developing” world than in wealthy countries but, once again, as with infertility, a preoccupation with infectious disease means that these conditions are barely noticed (but see Martin Prince:2003).

C. What counts as a “Knowledge Deficit?”

Food production is rarely linked explicitly to policies for global health care and yet, arguably, ready access to nutritious food should be considered the most fundamental right of all. The rapidly expanding introduction of GMOs (genetically modified organisms) into agricultural practices worldwide raises a group of conflicting moral issues that have a bearing on local nutrition, a situation well illustrated by a case study from Oaxaca, Mexico.

The origin of all maize and corn grown in the world today is Mexico, where the genetic diversity of the plant was first systematically cultivated. And Mexicans continue to derive 80% of their nutrition today from maize and maize products. The Mexican government prohibits the commercial planting of any GM maize or corn out of a concern
that such crops will adversely affect the biodiversity of native varieties known as “landraces.” There is also concern in Mexico that GMOs have not been sufficiently researched scientifically and may contain allergens or other toxins that affect humans adversely.

In 2000 it was discovered that a transgene from a genetically engineered corn variety produced in the United States and Canada had accidentally crossed into a maize crop grown by farmers in Oaxaca. A petition was brought by farmers and environmentalists to the Commission on Environmental Cooperation associated with NAFTA, the free trade consortium involving the United States, Canada, and Mexico. The CEC was set up specifically for the purpose of assessing complaints about the environmental impact of trade activities under NAFTA. This particular complaint was recognized as valid, and hearings were set up following preparation of background papers on the supposed effects of “current and future varieties of transgenic maize on the genetic diversity of landraces and wild relatives of maize, on agricultural and natural biodiversity in the region, on human health, on the economics, social values and cultural identity of the Oaxacan farmers” (Brunk:2006). Conrad Brunk, a philosopher and a member of the CEC advisory group, reports that the hearings were an extreme example of insurmountable misunderstandings between “experts” and the so-called “non-experts” – the campesinos.

In their papers the scientists argued, not surprisingly, that DNA technology is not that different from traditional forms of hybridization, that the presence of new transgenes in Mexican maize should come as no surprise, and in any case there was no reason to suppose that they would be any more harmful in the Mexican setting than in North America (where it was assumed that no harm had been done). The campesinos made it clear that the science was irrelevant to their most important concerns. What was “at risk” for them was the cultural and religious integrity of maize as an ancestral heritage – the product of 2000 years of cultivation of what was originally an inedible weed, teosinte, to produce over sixty different varieties of highly nutritious maize suitable for many different micro-climates and ecosystems. Camesinos bear a sacred responsibility for good stewardship of this heritage they argued and the probabilistic language of risk was not acceptable to them. The very presence of the transgene in their maize was already an
actualized harm – a contamination of their cultural heritage accomplished without their consent (2006:182). As Brunk points out, this constituted “paradigmatically unacceptable risk even in liberal democratic ethics.” However, because the hearing took place under the terms of the NAFTA agreement it had to abide by its terms. The only way that risk could be established was by conventional risk assessment science that ascertains whether unacceptable risk of harm is posed directly to human, plant, or animal health, or to the environment by the GMO transgene. Quantifiable variables alone could be considered, and “soft” cultural, religious or metaphysical considerations were rigorously excluded. The values of scientific expertise trumped all else, even when sound scientific findings were not available. It is acknowledged in the final report that the transgene is regarded as a contamination by the Mexicans, and the government moratorium on planting of transgenic crops was upheld, but no doubt provisionally, until further research is carried out.

Farmers throughout Central and South America are in touch with one another in connection with the looming threat posed by GMOs. They are well aware that not only are their cultural heritages under dire threat, but so too is their current means of livelihood. Should it be demonstrated that no immediate risk is posed by GMO crops, then Monsanto and other companies will be free to pry their way with their terminator seeds into the lucrative agricultural markets of the Americas, forcing farmers, most of whom participate in local cooperatives, to become peons working in the service of agribusiness. Their invaluable knowledge about ecosystems and the biodiversity of maize and other crops will be rendered useless; they will no longer be independent small scale farmers, and they will have to buy back their home grown GMO crops, no doubt at exorbitant prices, to feed their families.

Brunk points out that in contemporary society we have produced professionalized experts in the “normative sciences” including economics, management theory, and applied ethics. The assumption of these experts is that ethical and moral matters can be resolved by applying universally recognized values of what is good and right. However, these are the narrowly defined values of perceived benefit and avoidance of harm applied to the implementation of the biosciences. Drawing on the political theorist, Jeffrey Stout, Brunk argues that a narrowly defined bioethics should be replaced by open negotiations
among competing sets of values and, further, that scientific “experts” must be made aware of their own knowledge deficits including, of course, the enormous political repercussions associated with rational decision making based on decontextualized algorithms about risk assessments.

Summary

The three cases illustrate how, prior to the commencement of the health related and technological interventions outlined above, little or no discussion took place with the people who would be primarily affected. There is, it seems, an assumption of a knowledge deficit on the part of local populations that cannot be overcome with the result that any input from them is deemed irrelevant. However, it can equally well be argued that the “experts” have a remarkable knowledge deficit about the lives, hopes, and shared knowledge of the people who will be affected by the interventions. Further, the experts labor under a misconception that the biosciences, with their narrowly defined, decontextualized approach to knowledge and practices are sufficient to judge what is right and in the best interests of local people.

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