

A DIFFICULT BALANCE: DECISIONS IN HEALTHCARE

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ABSTRACT

As humans, we have a number of basic needs: air, water, food, shelter. While these needs have not changed, our ways of meeting them have evolved with our societal arrangements. These changes in the ways our needs are met require infrastructure. Secondary to the emerging infrastructure that has come with increasing urbanization have been additional capabilities. Many people have come to see the provision of these capabilities as needs or rights. Among them is healthcare. While this author is in complete agreement with the ideal of making access to healthcare universal, the concept of what that means bears closer examination.

The World Health Organization (WHO) defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” Such a broad definition may encompass any number of what will be referred to here as emerging needs, including the healthcare referenced above, as well as education, security and certain personal, political or religious freedoms, among many others. This state of physical, mental, and social well-being is also not likely to be defined in the same way for each individual, group, or culture. The balance in this system becomes difficult because there are multiple perspectives on what would constitute an ideal healthcare system, and perspectives may naturally change with circumstances.

The needs range across a very broad spectrum. We are entering a time of incredible divergence in our medical capabilities. On one hand we are moving toward an era of personalized medicine, in which we hope to provide medications for a specific genetic make-up. On the other hand, we are battling new or more resilient outbreaks of old foes such as cholera, dengue fever, and malaria. For participants in the healthcare system, including healthcare providers, public health practitioners, non-governmental organizations, and pharmaceutical companies, these questions and needs must be addressed on a global scale. As suggested by the WHO, we are a single planet whose populations have become interconnected enough to require the participation of all players in preventing disease and promoting health. The movement toward public-private partnerships, with implementation through grassroots organizations is likely to bring us the farthest in hearing the voices of the many, and understanding how to define, prioritize, and meet those needs. It is also important to consider the broader context within which that healthcare system works on a global scale. This paper will suggest ways in which systems thinking can “make a difference,” to echo the conference theme, by helping the various efforts in public health and individual health see the impact of multiple efforts together, so that they can be more complementary, or at the very least not work at cross-purposes.

Keywords: health, healthcare, healthcare system, global health, pharmaceutical, public health

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THE GLOBAL ENVIRONMENT

As humans, our basic needs include air, water, food, and shelter. While these needs have not changed with time, our ways of meeting them have evolved with our changing social systems and consequent living arrangements. Our air quality sometimes needs to be controlled. Our water supply may be cleaned and supplied through plumbing, or if the water is not cleaned, it may have become a source of disease. Many of us need food supplies beyond that which we can grow or raise ourselves. Not all of us build our own dwellings. These changes in the ways our needs are met require infrastructure.

Secondary to the emerging infrastructure that has come with increasing urbanization have been additional capabilities. Many people have come to see the provision of these capabilities as needs or rights. Among them is healthcare. While this author is in complete agreement with the ideal of making access to healthcare universal, the concept of what that means bears closer examination.

The World Health Organization (WHO) defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (Preamble to WHO Constitution, 1946). This broad definition may encompass any number of what will be referred to here as emerging needs, including healthcare, education, security and certain personal, political or religious freedoms, among many others. This state of physical, mental, and social well-being is also not likely to be defined in the same way for each individual, group, or culture. Interestingly, individual health security, with a focus on “the role of primary healthcare and humanitarian action in providing access to the essential prerequisites for health” is the planned topic of the WHO’s 2008 World Health Report (The World Health Report 2007, p 9).

In the meantime, the World Health Report 2007 is entitled, “A Safer Future.” It espouses, among other assertions, that “Today, the public health security of all countries depends on the capacity of each to act effectively and contribute to the security of all. The world is rapidly changing and nothing today moves faster than information. This makes the sharing of essential health information one of the most feasible routes to global public health security,” (p. 13). The emphasis here is on the prevention of pandemics, biological terrorism, and other global threats. However, examined more broadly, one interesting emphasis of this report is the pointed recognition of the responsibility of every country as a global player. There seems to be an emerging recognition of all nations as having a voice in our collective future as a planet. Similar arguments about the interdependence of peoples and power have been made in sociological circles as well (Piven, 2008).

As a global community, we seem to have evolved in our thinking. Generally discussions of global issues in the past started along the lines of separating “haves” and “have nots” from a material, industrial, or technological perspective. As the world became increasingly communicative internationally, and also moved through stages of relationships that included imperialism, colonialism, and defining “developed” and “developing” countries, we seem to have also moved through mindsets that went something like this, from the perspective of the “aggressors” or “philanthropists,” depending on one’s perspective.

1. We’re here to take over.
2. We’re from the Empire and we’re here to help.

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3. We're giving you everything you need to be just like us. What's the problem?
4. Maybe you have some perspective on what's needed.

Hopefully we are finally moving toward a fifth mindset that can look more like a full partnership, in which there is recognition of the roles, responsibilities, perspectives, legitimacy, and importance of all of the people involved in this complicated discussion regarding our collective future as human beings.

It is this interdependence of peoples, perspectives, and institutions that systems thinkers can and, I would argue, should represent. The broad thinking that captures the importance of each component in a total system can make an important contribution in advancing the discussion among diverse groups of healthcare providers and healthcare consumers. Systems practitioners who are part of the organizations that contribute to healthcare, as well as systems thinkers who sit outside of the organizations, have the potential to influence efforts by affording greater understanding of diverse perspectives and representing the influence that each may have on the total result that all can build together.

How “we” (humans) have that conversation inevitably comes down to a question of who represents the interests of many. Individuals may have the opportunity to participate in a system, but it is likely to be created by relatively few people, although it is sustained by all of us. Indeed, some argue that individuals should not be seen as the main driving force for health improvement at the population level (Beaglehole, 2005). While as individuals we often seem capable of negotiating relationships among diverse peoples, once we create officialdom, whether governments, religions, or healthcare systems, we seem to lose our ability to consider individuals, and in the process probably lose some of the benefit that was originally intended with the design of the institution itself. Nowhere may this be truer than with those institutions that are supposed to provide for our physical lives. From conception through death, whether maintaining health or fighting disease and deterioration, there are virtual strangers advising, cajoling, monitoring, measuring, praising, scolding, excising, implanting, or telling us to ignore those parts of our lives that we as individuals experience the most tangibly. Institutions and organizations attempt to meet the healthcare needs of those varied individuals, in different ways. Systems thinking can provide an informed perspective on the interactions among those organizations and institutions to help them work more effectively as circumstances and needs continue to evolve.

THE DIFFICULT BALANCE

The balance in providing healthcare becomes difficult because there are multiple perspectives on what would constitute an ideal healthcare system, and multiple players in providing it. In addition, perspectives may naturally change with circumstances. Worthy goals may include

- all people receiving some basic level of medical care
- all people receiving appropriate screening and monitoring to maintain healthy life
- sicker people receiving more intervention
- breakthrough medicines, technologies and surgeries continuing to be discovered and developed
- breakthroughs being available to everyone who could benefit from them

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- people of working age being able to continue to work and contribute to the economy, and therefore able to receive needed treatment and health maintenance
- children and adolescents being afforded all of the appropriate vaccinations and/or health maintenance and disease prevention possible so that they have an opportunity to live long and healthy, productive lives
- older people being provided all of the life sustaining treatments that exist, including remedies for the ailments created by our emerging lifestyles
- cures being found for the conditions we ourselves help create from the environmental problems caused by industrial changes and other human factors
- cures being found for all of the newly emerging bacteria and viruses that are resistant to the therapies we've already created
- universal access to clean water, nutritious food, and hygienic living conditions
- people having some choices in who provides care for them, what kind of care they want, and how and where they should receive it, since we know that simply making services available does not guarantee that they will be used optimally

These are a few of the many desirable goals on a wish list that could be as long as the list of people who inhabit this planet. But who gets to make those choices for the many? And which needs are the most important to answer first?

As suggested above, those needs range across a very broad spectrum. We are entering a time of incredible divergence in our medical capabilities. On one hand we are moving toward an era of personalized medicine, in which we hope to provide medications for a specific genetic make-up (FDA, 2007). On the other hand, we are battling new or more resilient outbreaks of old foes such as cholera, dengue fever, and malaria (Silberner, 2008; The Observer) These questions and needs must be addressed by a healthcare system or systems on a global scale. As suggested by the WHO report, we are a single planet whose populations have become interconnected enough to require the participation of all players in preventing disease and promoting health.

Healthcare is arguably a complex adaptive system (Rouse, 2007), capable of learning and self-organizing, with no single point of control. This perhaps gives the greatest hope of answering the many diverse needs. It is also the source of some of the greatest difficulty in making the system "work." The people who create the technologies and treatments are not the people who determine some of the treatments needed for a patient and prescribe them, who in turn are not the people who often pay for them, who in turn are not always the people receiving the services and treatments. The functions of these groups could be simplified, for the sake of discussion, into supply, control, payment, and demand, with the realization that some groups serve more than one function. Each group often has a different interest or goal that it serves in order to contribute its part in the healthcare system. Furthermore, the groups may not all define optimal health in the same way. Some groups may be trying to maximize the benefit to the individual by prolonging comfort or trying to prolong life. Other groups may be trying to ration limited resources to achieve a societal goal. Some may be trying to maintain profits for shareholders or minimize costs for funding agencies. Some groups may be trying to meet the needs for the greatest number of people, or for the people deemed to be able to help their society the most, e.g., by contributing to the current or future economy. It is easy for these objectives to come into conflict, and for each party to see only part of the picture. In the current environment, given

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the institutions available, each objective and perspective has legitimacy that needs to be recognized if genuine progress is to take place toward finding solutions to current and emerging health issues. Systems thinkers within, or working among, these organizations can provide a more objective view of the dynamics in the healthcare system and the interplay of groups and their interests.

THE LESSONS FROM HIV

We learned many lessons about the interplay of culture and healthcare in the early fight against HIV. The virus spread through diverse populations, mutating rapidly. Many voices clamoured to be heard. Patients were frightened and desperate. Doctors were fighting something they hadn't seen in medical school. Researchers frantically worked to find the organisms and mechanisms responsible for causing illness and death. Pharmaceutical companies, biotechnological firms, research institutes and governments tried to develop treatments and preventions based on emerging information. Conferences featured late-breaking sessions so that the very latest discoveries could be shared. As knowledge grew regarding the cause of AIDS and the potential treatments for HIV, patient groups and advocates became vocal about their priorities for the discovery and provision of treatment. There were demonstrations trying to force more rapid approval of medicines, movements to increase production of vaccines, attempts to promote barrier contraceptive use and abstinence, battles over the production and distribution of antiretroviral therapies, and a realization that we had entered a new age of pandemics capable of reaching around the globe.

Those patients and their supporters who were well-educated and/or well-connected in demographic communities and through the internet were able to transform doctor-patient relationships into partnerships seeking cures and more effective treatments. Some patients were presenting their views at medical conferences. Some patients and their advocates were helping to promote participation in clinical trials. Some patients and doctors experimented together with herbal treatments and health regimens in conjunction with antiretroviral therapies. But these were not the only faces of the pandemic. There were so-called disenfranchised populations as well. The patterns of infection and disease differed among patients, as did their levels of trust in the medical community. There were accusations of HIV having been engineered to wipe out segments of the population. There were disputes over whether HIV caused AIDS. There was increasing realization that in addition to the obvious human tragedy for the individuals and their families, this pandemic brought to light many cultural issues beyond the disease itself – relationships among men and women, discussions of sexual taboos and lifestyles, economic issues around providing therapy for uninsured people who at that time were unlikely to be able to work again if they ever had, issues of discrimination, questions of moral high ground. These issues have not all been solved, but we began to understand that we were working in a much larger arena than one infected human body at a time.

In the meantime, attempts to make treatments and prevention more widespread in countries that were the most impacted by HIV and AIDS have been continuing to teach us important lessons about healthcare on a global scale. If cultural and social situations within a few countries were diverse, circumstances around the globe writ large the social and political variables that had to be considered. The impacts of the pandemic internationally were wiping out swaths of populations during what would normally be their most economically productive years. We (in the West) had to recognize that some of the circumstances that allowed for such devastation had been set up by outside countries' influence on the more traditional family structures and economic arrangements of the countries now hit hardest by the pandemic. For example, the advent of trucking routes in Africa led to the separation of families for months at a time, with associated increases in prostitution and multiple sexual

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relationships outside of marriage along the trucking routes. Declarations of traditional polygamy as taboo likewise left women and eventually children who would previously have been part of a family unit without economic or social support and with few ways for women to become educated and support themselves and their children. The sex trade in Asian countries that had previously been agrarian saw the rapid spread of HIV and AIDS, along with trafficking of younger and younger adolescents and children in the vain belief that they would be less likely to be infected. As each country assessed its own growing infection rate, some governments denied that HIV had entered its borders, some countries refused antiretroviral treatment even when it was offered at cost or free. Some countries confronted the pandemic head-on with educational programs and deep commitment to work with anyone who legitimately had treatments to test within their borders, as long as the benefits would remain after the clinical trials were over.

From the perspective of research and treatment, there were profound questions about potential unintended consequences. What if a vaccine were found and given widely, but it was only partially effective? Would sexual partners stop using condoms and other measures to prevent the spread of HIV and be at greater risk of infection? Furthermore, would we cause even more treatment-resistant mutations of the virus to be spread in this way, and ultimately make the pandemic even more intransigent? Likewise, if we began giving antiretroviral therapy, and then discovered that patients could not receive a steady supply of their medication, how much would we again be contributing to the spread of drug-resistant virus? We knew that consistent therapy was key to controlling the virus for longer periods of time. From the beginning, there was an ethical obligation to all patients to treat them for life. Mobile and remote populations would always have to have access to ongoing supplies of medication. What if shipments of drug were seized and sold on the black market? How would we be able to track where the drugs went and what happened to the patients who received them, and how would we ensure that more drug reached the original patients in time? We had to think about, and sometimes build models to predict, how effective a vaccine or treatment would have to be, in what percentage of the population, over what period of time, to be more beneficial than harmful.

In addition to these broad issues, we had more specific concerns around getting medicine to patients on the ground. The vaccines and therapies needed to work in predominantly different mutations of the virus than those that were found in Western populations. Assuming that they worked in the laboratory, there were also fundamental aspects to delivering successful ongoing treatment in a hospital, clinic, and/or village. Many of the regions needing therapies had tropical climates that could affect the stability of the medicines and vaccines. In other words, the medicines had to be tested to see if they would become ineffective due to chemical breakdown in extreme heat and humidity. As described above, it was also imperative that patients who started on therapy remained on it. They would have to have blood tests to ensure that the medications continued to work, and would have to be given new therapies when the old ones stopped working. The tests that would check the amount of virus in their bloodstreams likewise had to remain chemically stable in tropical climates and had to be inexpensive enough and uncomplicated enough to be able to reach more remote local clinics rather than just being used in metropolitan hospitals if use were ever to be widespread. The needles that would be required for blood tests and vaccines were designed for single use, which was impractical in a place with few resources. Methods had to be developed to sterilize and reuse equipment. Patients also had to be found. With the vast fear of the disease and the strong biases against HIV within many local communities, patients were frightened of being tested and identified.

Ultimately, efforts around treatment and prevention had to work hand-in-hand. Cooperation among grassroots organizations, governments, employers, and peer networks within cultures and countries led to successful implementation of prevention and treatment campaigns. The

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voices of the many had to speak to one another, and work toward solutions that were sustainable in the lives of patients and their families and communities. Uganda's factories and Thailand's military were two successful organizations that confronted their rising infection rates openly and worked to provide education, prevention and treatment. They were able to decrease their infection rates while infection rates continued to rise elsewhere.

Twenty-five-plus years into the pandemic, we have seen progress, with simpler tests, more widely available therapies, and increasing numbers of children born uninfected. However, there are still an estimated 33.2 million people infected with HIV as of December 2007. An estimated 2.5 million people were infected that year, and about the same number (an estimated 2.1 million) died of AIDS in 2007. About 2.5 million children under the age of 15 are estimated to be living with HIV. (UNAIDS, 2007)

GROWING EFFORTS

As our global consciousness has been raised, we have been targeting other areas of concern with more visibility and larger funds. These are sometimes collectively known as the "neglected diseases" that still affect large populations. There has been some movement toward public-private partnerships to work on these diseases that have been eradicated in some areas of the world, while still ravaging others. Implementation of treatments and wider solutions for these health problems through grassroots organizations (The Observer, 2008) may be likely to bring us the farthest in again hearing the voices of the many, and understanding how to define, prioritize, and meet diverse needs. But it is unlikely to be a simple or speedy process. If we consider the broader context in which these diseases have been allowed to thrive, it is clear that healthcare is again part of a much larger milieu. As explained in a public health manual, "health inequities involve phenomena outside of science, scientific measurement and bureaucratic management," (Hofrichter, 2006). The myriad factors affecting healthcare discrepancies are part of a complex system that makes up a standard of living. Consider the following illustration, outlining the impact of social injustice on disease and mortality (Figure 1), as one example. The inclination for someone creating health policy might be to feel overwhelmed by the apparent need to try to fix everything, and perhaps to conclude that nothing practical can be done, or to try to focus on one thing that can be done, without necessarily considering the other elements. Either approach is likely not going to make much improvement. However, the role of systems thinking in "making a difference," to echo the conference theme, could be in helping the various efforts in public health and individual health see the impact of multiple efforts together, so that they can be more complementary, or at the very least not work at cross-purposes.

For more of a systems approach, consider Figure 2. This second diagram is by no means a comprehensive picture of needs or infrastructure. Rather, it is meant to represent the various types of social conditions that often build together as change takes place within a society. What began as an understanding of basic infrastructure needed to deliver medicines on an ongoing basis to populations who live in remote areas is evolving into a greater understanding of how the interdependence of many aspects of society can work together. The model for each system, culture, society, or circumstance is likely to vary, but some fundamental possibilities are represented in Figure 2. Clean water and better nutrition alone can increase the health and resilience of a population. If healthcare, and presumably health, improve, then the population could increase, or decrease, depending on whether or how soon other factors such as contraceptive use are part of the available healthcare. Often an increased use of contraception affords women more of an opportunity for education. Likewise, healthier children may mean an increase in the need for schools, or larger schools, at the elementary and secondary level. An increasingly educated population can provide for more of an opportunity for technological development. Depending on the type of

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technology and how it is introduced, it could have an impact on desired family size (e.g., fewer people needed for some types of work, more education needed for fewer children). Technology can also lead to greater demands on healthcare, for example, if hazardous working conditions or unhealthy environmental impacts result from increased industrialization. Outside forces such as epidemics may still have an effect on population size. Potentially, the effect could be smaller if adequate nutrition, clean water, and good healthcare are available. However, increasing mobility and urbanization can lead to faster and more far-reaching spread of disease.

The point of thinking about these interrelationships is not to halt change or limit access to it, but simply for participants, such as healthcare agencies, grassroots organizations, and governments, to begin thinking earlier about how the changes they are working toward might be implemented in the most advantageous ways in conjunction with one another. I believe that this is some of the promise public/private partnerships afford. With more stakeholders at the table, working together and potentially each working on a variety of efforts, there may be more opportunity for greater understanding and more far-reaching benefit.

This type of dialogue is needed in many areas, about many health issues, not just the ones in what we often term the “developing” world. Many developments continue in more heavily industrialized countries as well. A recent article in the *Wall Street Journal* highlighted the difficulties of paying for chronic diseases that are on the rise among aging populations, using Alzheimer's disease as one example of what the paper characterized as, “a rising tension that pits the cash-strapped entities that pay for healthcare against patients and drug companies. The entities that pay for healthcare in Britain increasingly say their limited budgets are forcing them to weigh the benefits of treatments against their cost. Patients and drug companies say such rationing could deny useful drugs to people who need them.” At stake were the calculations that the National Institute for Health and Clinical Excellence (or NICE) had used in determining that a drug did not show enough effect to be included in its list of approved medicines for some patients. NICE was complying with the order to reveal its calculations, but added that the ruling would “increase the complexity of our drug appraisals in some cases and they may take longer as a result.” (*The Wall Street Journal*, 02 May 2008). Again, we have an example of those interested in trying to maintain a basic level of health for a population versus those who are interested in helping the individual. Philosophically, we can see the need for fair distribution of resources. When our loved one is involved, however, the picture can look quite different.

Beyond a specific issue of care for particular patients in a certain demographic, there is the more general issue of how to balance care across the demographics of a society. As with the issues in less industrialized areas of the world, the more heavily industrialized areas also have choices, which are likely to impact their future development. Serious questions arise as populations age and keepers of public funds try to calculate who is contributing to the resources that sustain people who cannot work or have retired. Factors that increase life expectancy versus those that increase or sustain productivity are invariably part of the equation. Healthcare agencies are increasingly aware of the need to encourage more participation from patients and potential patients to help in this balance. Healthier lifestyles and improved disease prevention can contribute to less demand on the healthcare system. But the potentially longer lives and greater demand for screening tests also need to be factored into the equation. Once again, different stakeholders may be involved in these separate but related areas of healthcare and more general welfare.

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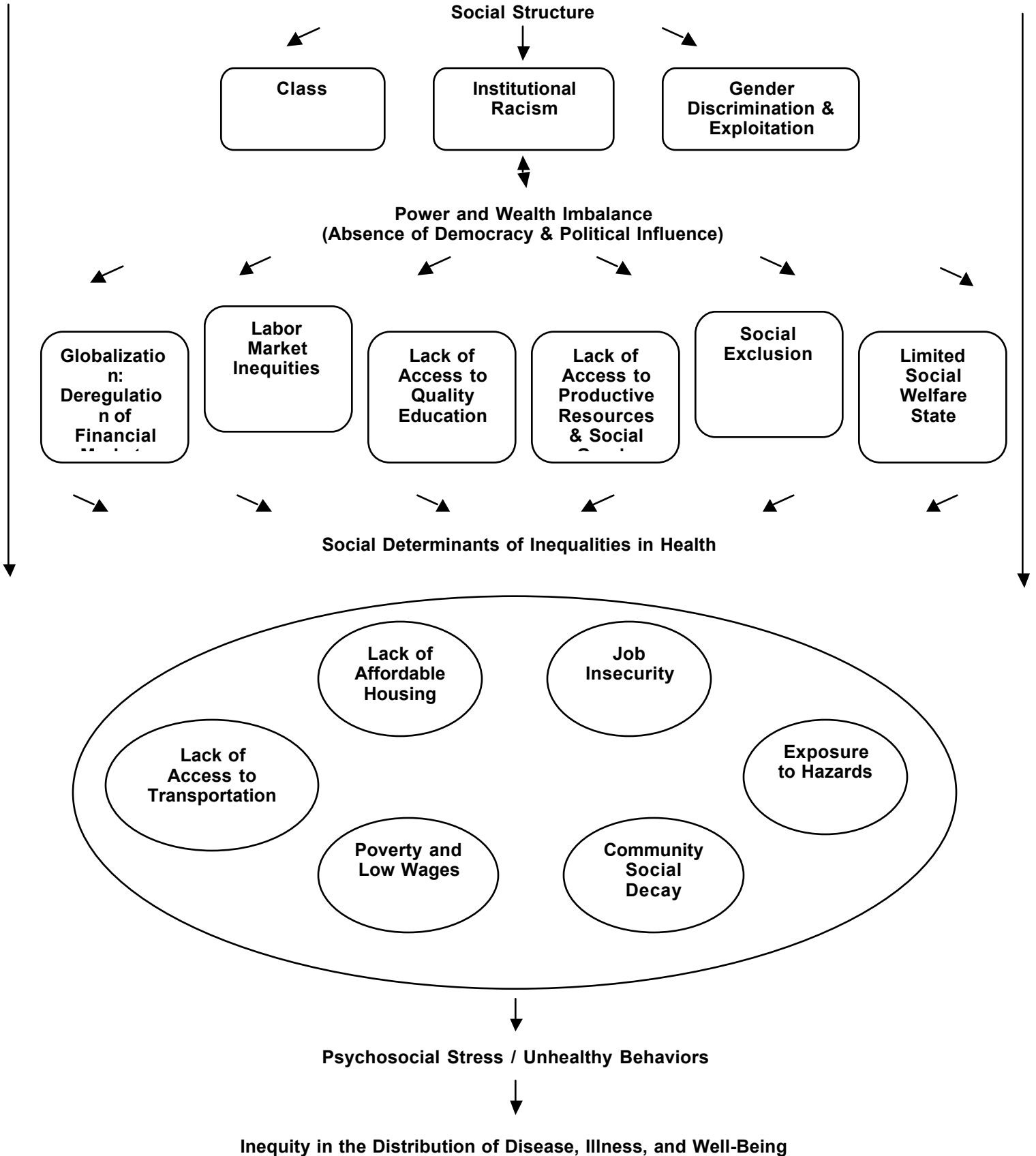


Figure 1. How Social Injustice Becomes Embodied in Differential Disease and Mortality Rates. (F Hofrichter, 2006, p. 245)

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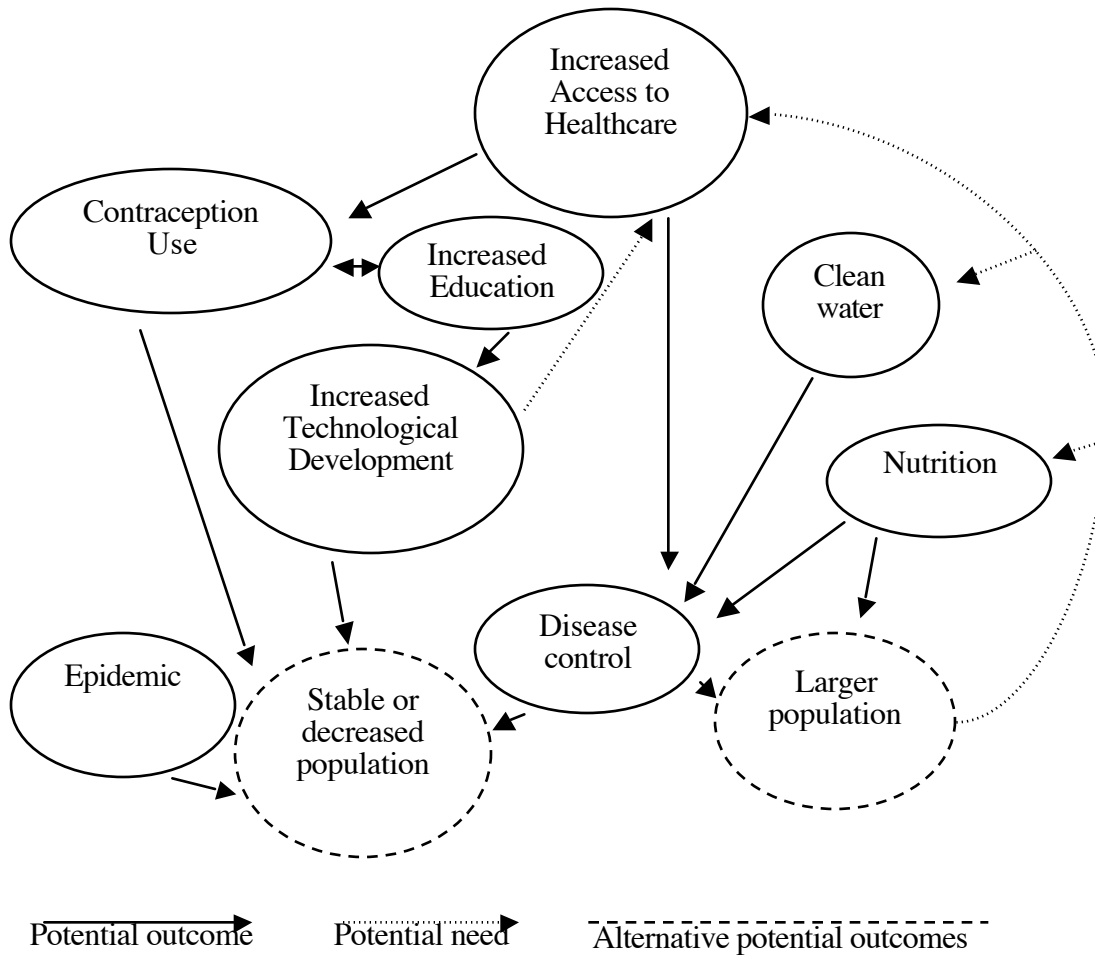


Figure 2. Some Potential Outcomes and Covariates of Increased Access to Healthcare and/or Disease Prevention

The picture is unlikely to become less complicated in the future. With the advent of increasingly specialized treatments that are desired for specific subgroups of patients, or “personalized medicine,” we face the need for even more specialized technology, from basic laboratory research, to testing in animals and people, to manufacturing smaller quantities on a more specialized scale. Along with the specialized medicines and devices come the special tests to determine which patients should receive which treatments. In addition to the issues around privacy, including concerns regarding the level of personal genetic information that may become available and out of an individual’s control, there are other aspects that have to be considered by governments, industry, and the public. The development of medicines and devices is highly regulated. The evaluation of safety and efficacy are accomplished in large measure by statistical evaluations that in the past have

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depended on clinical trials in patients deemed representative of the intended population for whom the treatments will become available. Even with strict controls, and extended studies after regulatory approval, rare events can occur when medicines are used in increasingly diverse populations. There is a continued effort to find better ways to predict rare events sooner, and hopefully understand how to identify patients who may be at greater risk from a rare side effect. But these methods often require large numbers of patients. With the advent of medicines specialized to very small groups of patients, we must consider how we will evaluate efficacy and safety, and how we (the collective “we” including patients and physicians) can balance the risk of what we know and what we don’t know about individuals, their genetic makeup, and what that implies for the medicines that will be of greatest benefit to them. We will also have to consider how many of these medicines will be available, based on the processes and resources that will be necessary to develop, evaluate, regulate, and pay for these specialized medicines. “We” includes patients, regulators, healthcare providers, and the public who will in some way have voting ability and the power of public opinion to say how their tax dollars, healthcare bills, and public research funds should be used.

As healthcare technologies continue to evolve, along with our definitions of desired health and basic healthcare needs, societies, cultures, and/or countries will have to determine the approaches and technologies that are the most appropriate for them. Decisions are made for populations through funding and regulation. Priorities may be set by political, religious and/or economic forces. The repercussions of these priorities can be examined to allow more informed decision making. Transparency will not be a panacea. There will be conflicting interests. We have not found ways to maximize benefits to everyone, all at once. It is doubtful that we ever will. It could be argued that it is not even desirable to be overly transparent about the value one is placing on some segments of society at the expense of others. However, the alternative seems to be a cacophony of voices vying for their share of the resources, not to mention the silence of those who may feel that there is no hope at all.

I believe that this type of dialogue is a huge opportunity for systems thinkers to become a much more public part of the discussion. With the advent of global communications through the internet and other popular sources, there is an unprecedented opportunity for more public discourse and far greater awareness of the complex issues that affect all of us as human beings. Ultimately, programs will be created and decisions will be made by finite numbers of people, but the more that those decisions can be informed by patients and populations who are the ultimate consumers, the closer we will come to achieving that difficult balance.

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