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Ethical Issues and Access to Healthcare

Abstract

Access to healthcare services is far from equitable and legitimately raises the question of justice. Healthcare insurance provides access for most Americans, but for the 15% without coverage, access to healthcare services is difficult at best. As limits are put upon the healthcare dollar at the same time that technology is advancing rapidly, the population is aging, and resources are shrinking, we must determine a just and fair process for allocating limited healthcare resources.

In his many books, physician and medical anthropologist Paul Farmer[1(p 18)] challenged his readers to focus on the ability to access quality healthcare and its benefits even if only at a basic level: "Lack of access to the fruits of modern medicine and the science that informs it is an important and neglected topic within bioethics and medical ethics."Although many factors contribute to barriers that impede access to healthcare, Farmer and many others identified poverty as the single most significant barrier.[2] This article explores how poverty affects opportunities to benefit from current healthcare services in this country as well as healthcare resource allocation issues.

• INTRODUCTION

In the conceptual framework of bioethics, the questions concerning access to healthcare fall primarily under the principle of justice (ie, fairness, entitlement to and equitable distribution of resources). Emanuel[3(p 8)] divided the issues of justice in healthcare into two different but related dimensions: access and allocation. *Access* refers to "whether people who are—or should be—entitled to healthcare services receive them." Discussion points about access include rights to healthcare, what constitutes entitled healthcare services, and barriers to these services.

Allocation refers to the process used to determine which resources will be distributed for healthcare within populations and for individuals. Allocation questions exist on three levels. The first level of healthcare allocation, the social level, relates to the amount of government resources that will be used for healthcare as opposed to other budget needs, such as defense or transportation. The second level, allocation at the point of healthcare service, involves decisions about the healthcare portion of the federal budget and how, where, and for whom those dollars will be spent. The third level of allocation concerns the individual patient.

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• ACCESS TO HEALTHCARE AND THE UNINSURED

In the United States, one of the more critical variables in determining access to healthcare services is health insurance coverage. Simply put, he or she who has the coverage has access to healthcare.

The US Census Bureau issued a report, *Health Insurance Coverage in the United States: 2002*,[4] that describes the extent of health insurance coverage and the characteristics of those who have or lack coverage. The report describes a number of factors that support access to healthcare as well as barriers.

In 2002, almost 85% of the US population reported having healthcare insurance coverage from employer-based insurance (55%), Medicaid, other means-tested programs (17%), or Medicare (13%). The remaining 15% of the population had no health insurance coverage of any type.[4] Although lack of health insurance does not entirely prevent a patient from receiving healthcare services, it certainly makes it extremely difficult. In its report, the Census Bureau includes a great deal of specific information on the characteristics of each group, showing even more about who has access to healthcare.

A review examining the characteristics of the uninsured identifies obstacles to access that are quite obvious and others that are more subtle. For example, almost 44 million Americans lacked health insurance coverage for the entire year of 2002. However, a much larger number, perhaps as many as 70 million, lacked coverage for either part or all of that year, resulting in an even greater problem of limited access to healthcare services.[4,5]

The single most influential factor contributing to the lack of insurance coverage is poverty. More than 30% of those at or below the poverty level had no insurance coverage, a rate double that for the total population. The near-poor fared little better, with almost 28% of those between 100% and 125% of the poverty level having no insurance coverage.[4] It is this pervasive influence of poverty on the uninsured rate that is so compelling. A review of other factors contributing to a lack of insurance shows that for almost every variable influencing the uninsured rate, the addition of poverty further increases the rate of the uninsured.

Gender has a slight impact on the risk of being uninsured. Overall, slightly more men than women lacked health insurance (17% vs 14%). When poverty was added to the data, each rate doubled, resulting in 33% of men and 28% of women having no health insurance.[4]

Federal legislation, particularly Medicare and the State Children's Health Insurance Program, profoundly influences the impact on uninsured rates, especially with respect to age. Because Medicare is an entitlement program for everyone older than 65 years, less than 1% of persons in this age range lacked some form of insurance coverage. Although the rate doubled for those in poverty, it still was less than 2%. At the other end of the age spectrum, coverage for the young has improved in recent years, but it has not reached the level seen with the elderly. Almost 12% of children younger than 18 years continued to have no health insurance coverage. If a child also happened to be poor, the risk increased to more than 20%.

Because our current system is heavily invested in employee-based health insurance, it might be assumed that people between the ages of 18 and 64 years (those most likely to be employed) would be more likely to have insurance coverage. Sadly, for all between the ages of 18 and 64 years, the rate of those uninsured was higher than for the young or elderly (13.5%-30%). For those in poverty, the chances of being uninsured increased to between 30% and 60%.[4]

Race is another factor that profoundly influences insurance coverage. In 2002, Hispanic and black Americans fared the worst, with 32% and 20%, respectively, not having health insurance. White and Asian Americans were less likely to be without coverage, with rates of 14% and 18%, respectively. However, poor whites and poor Asian Americans were twice as likely (at rates of 31% and 38%) to lack coverage as these groups as a whole. Poverty did not have as great an impact on blacks and Hispanics, but these groups did show increased uninsured rates of 26% and 43%, respectively.[4]

Irrespective of race, the most significant factors for insurance coverage were being foreign-born, poor, and not a citizen (61%). Foreign-born status alone almost tripled one's chances of being uninsured (13% for native-born and 33% for foreign-born Americans). When poverty was added to this comparison, the chances of being uninsured increased to 26% for native-born citizens and 55% for foreign-born citizens. The findings for foreign-born citizens showed that being naturalized correlated with a lower chance of being uninsured (17.5%). Again, poverty doubled this rate to 35% for poor naturalized citizens.[4]

Gender, age, race, and location of birth are characteristics that individuals cannot create or change. Two other factors significantly influencing insurance coverage that may be somewhat under the control of the individual were evaluated. Education had a profound effect on insurance coverage. Not surprisingly, lack of insurance coverage decreased with a rise in education level. The uninsured rate was 28% for those with no high school education, but only 8% for those with a bachelor's or higher degree. Poverty increased the percent of high school dropouts without insurance coverage by 10 points to 38%, but it quadrupled the percent of college graduates without insurance coverage to 32%.[4] It seems that education matters, but education is less important if one is poor.

As with education, employment status had a direct impact on lack of coverage. As shown by the findings,

18% of full-time employees go without insurance, with the rate increasing to 26% for the unemployed. Poverty also affected the lack of coverage here, but in an unexpected direction. Whereas 38% of the unemployed poor had no coverage, this percentage grew with employment. An amazing 49% of poor full-time employees were uninsured.[4] This statistic alone raises serious questions about the effectiveness of an employer-based health insurance system.

• MORE ABOUT THE UNINSURED

In the US healthcare system, being uninsured is a major impediment to obtaining healthcare services. What else do we know about the 15% of the population who are uninsured? From 2001 through 2004, the Institute of Medicine's Committee on the Consequences of Uninsurance conducted an assessment of the health, social, financial, and economic consequences of being uninsured and its effects on individuals, families, communities, and society. From this analysis, the committee published a series of six reports.

The first report, *Coverage Matters: Insurance and Health Care,* described what it means to be uninsured.[6] The committee reported that several commonly held myths about the uninsured bear no basis in fact. A number of truths about uninsured Americans and their healthcare are presented in the following discussion.

Although persons without insurance have some ability to obtain healthcare, in reality, the uninsured are more likely to have no regular source of healthcare, to do without needed healthcare, to take advantage of fewer preventive services, and to receive less treatment for chronic illnesses.[6] Delays in treatment because a patient is uninsured can have deadly consequences. In fact, the risk of death for uninsured women with a diagnosis of breast cancer is 30% to 50% greater than for women with breast cancer who are insured. Overall, outcomes for adults with no health insurance are grim, with 1 study reporting a 25% greater chance of dying for uninsured adults than for adults with health insurance.[7]

Another commonly held misconception states that the ranks of the uninsured are made up of young adults who are basically healthy and who refuse health insurance because they do not feel they need it. In fact, only about 4% of workers between 19 and 34 years of age have declined to accept health insurance available through their employers.[7] It is more likely true that young adults between the ages of 19 and 34 years do not have insurance because they are ineligible, because they were only recently hired, or because the firms for which they work do not offer health insurance coverage.

Perhaps the most astonishing myth about the uninsured is that they do not work, and therefore they and their families have no coverage. The truth is that more than 80% of the children and adults who are uninsured come from working families. In fact, even in families with 2 full-time wage earners, almost 10% still are without health insurance.[7]

Increasing numbers of immigrants have been blamed for the growing uninsured population. Although it is true that the foreign born do have increased chances of being uninsured, immigrants make up only about 6% of the entire uninsured population, whereas more than 80% of the net increase in the number of uninsured individuals are US citizens. It also has been noted that the uninsured rate for immigrants decreases with increasing length of residency.[7]

• SOCIETAL IMPACT WHEN THE UNINSURED CANNOT ACCESS HEALTHCARE

So what happens when the uninsured get sick and end up in US emergency rooms and hospitals? We healthcare professionals know that the door of access to healthcare services, although not widely opened, is not completely closed, and that these patients do receive care. Each year, federal, state, and local governments, along with numerous charitable individuals and organizations, provide billions of dollars to support healthcare for the uninsured. But this care often is of lower quality and results in poorer outcomes than that provided to those who have health insurance coverage.

The price paid for this limited access to healthcare services is great, both for the uninsured themselves and for the communities in which they live. An estimated 18,000 premature deaths occur each year because of the many uninsured individuals. When faced with acute illnesses, uninsured children and adults experience higher morbidity and poorer outcomes because they are unable to access appropriate or timely services. Among the more than 8 million chronically ill and uninsured individuals, increased morbidity and poorer outcomes will result from the lack of appropriate and timely services. Of the 41 to 45 million adults and children who are uninsured, and therefore less likely to receive preventive or screening services, negative health outcomes are more likely.

In addition, the consequences of large numbers of uninsured individuals are felt in the communities where they live. No insurance means less financial security and more stress for uninsured persons and their family members. In communities where the number of uninsured individuals is higher than average, healthcare services risk becoming less available, and public resources often are overburdened. As these problems spread to larger communities and the country as a whole, all Americans feel the impact on the healthcare system.[8]

• ACCESS PROBLEMS—EVEN WITH INSURANCE COVERAGE

Although it is true that the lack of healthcare insurance is the most significant obstacle to healthcare access, even our current healthcare insurance mechanisms do not eliminate access problems. Employment-based insurance, the mainstay of healthcare coverage in the United States, by its very design, encumbers quality healthcare. Because insurance is tied directly to employment, findings show that coverage, and often providers, change when individuals move from one employer to another. This discontinuity of services can have an impact on the quality of care for individuals and family members. The advantage of "family coverage" disappears when family status changes. For nontraditional families, coverage often is nonexistent. Ultimately, the extremely high administrative costs of maintaining the US employment-based system may not be sustainable. An increasing number of small businesses are declining to offer coverage because of the expense, thus further limiting access to healthcare.

Medicaid and other means-tested programs, such as the State Children's Health Insurance Program, have their own problems. Unlike employment-based coverage, these programs cover individuals and do not offer family coverage, resulting in families composed of both insured and uninsured individuals. The process of determining eligibility for these programs is cumbersome and costly. Because reported income is the primary variable determining eligibility for these programs, income evasion sometimes occurs and must be addressed. As a result, application processes are burdensome and often impose a stigma for applicants, thus making it difficult for those who are legitimately eligible for services. Individuals may frequently move in and out of the program as their eligibility status changes, resulting in discontinuity of care.

Because Medicare has a single eligibility requirement—being 65 years of age—it does not impose the same obstacles to access that occur with both employment-based coverage and Medicaid. One problem with Medicare, however, is the rapidly expanding cost of the program as the population ages and the number of enrollees multiplies. In addition, because it is an entitlement program, few restrictions have been placed on coverage of high-tech procedures. This flaw in the Medicare program has resulted in a failure to consider benefits in relation to the cost of technology. With increasing numbers of Medicare recipients and escalating technology costs, this program is not sustainable indefinitely and projects a situation that has serious consequences for the future.

In summary, access to healthcare services in the United States is far from equitable, raising the question of whether it is just. The one clear variable that offers individuals access to the healthcare system is having some form of healthcare insurance. But for the 15% of the population who have no coverage, access to healthcare services is limited at best. The demographics of the uninsured raise serious questions about the justice of the US system, because lack of insurance appears to affect persons in specific categories, primarily the poor, but also minorities and immigrants. Even those who do have health insurance may face difficulties gaining access as their plans fail to accommodate employment changes, increasingly diverse lifestyles and family arrangements, complex administrative structures, and the need to evaluate the cost of technologies relative to their benefit.

• ALLOCATION OF HEALTHCARE RESOURCES

In addition to health insurance coverage and access problems, we also face questions of fair and just allocation of available healthcare resources and of determining how to distribute resources within populations and to individuals. A number of variables contribute to these growing concerns. First, there is a ceiling for available healthcare dollars. Because the gross domestic product (GDP) must address a number of social needs in addition to healthcare, it is unreasonable to expect that healthcare will receive unlimited funding. We can anticipate a time when the portion of the GDP allocated to healthcare will stop rising. That moment may come soon because the United States currently spends the largest percentage of its GDP on healthcare, as compared with all other industrialized nations. Also influencing the availability of healthcare dollars is the current technology-driven healthcare environment, with its continuing development of new and better treatments, medicines, and technological devices at ever-increasing costs.

Second, although it is clear that healthcare expenditures cannot inflate unchecked, the demand for healthcare services continues apace. Advances in the treatment of injury and disease have increased the numbers of individuals who are living years and decades longer with complicated chronic illnesses and disabilities. Improved healthcare has resulted in extended average life spans and a burgeoning elderly population with increasing health problems.

Finally, this growing need for healthcare requires trained healthcare professionals, the largest group of which is nurses. The projected nursing shortage in the future will have an enormous impact on the availability of healthcare services.

Eventually, the need for healthcare services will bump up against the financial or material limits of available healthcare resources. At that time, the nation must address the just and fair allocation of limited healthcare re-

sources. Writings on the principles of justice can offer some insight into how these questions might be answered.

• DISTRIBUTIVE JUSTICE AND LIMITED RESOURCES

Beauchamp and Childress[9(p 227)] begin their discussion of justice within healthcare by offering a foundational grounding for this principle. They assert that "common to all theories of justice is a minimal formal requirement traditionally attributed to Aristotle: Equals must be treated equally, and unequals must be treated unequally." Logically, when all circumstances for all persons are equal, everyone should be treated equally. The more difficult and more common situation in healthcare is that in which all circumstances are not equal, requiring unequal but fair treatment for everyone.

Numerous theories of justice have been proposed to help address the distribution of limited healthcare resources. Common to most of these theories are the following proposed principles of distributive justice:

- To each person an equal share
- To each person according to need
- To each person according to effort
- To each person according to contribution
- To each person according to merit
- To each person according to free-market exchange[9]

These principles provide a worthwhile starting point for deciding how to distribute limited resources. They help justify a way to make these difficult choices. However, they do not always offer solutions, and at times can create even more issues (eg, where 1 principle supports 1 decision while another supports a different choice altogether). Thus it might prove useful to prioritize these principles based on resources needing to be limited, and if necessary, to use more than 1 principle in a logically ordered process.

One example of this is the allocation of donor hearts for transplantation. Not all persons can receive a heart because there simply are not enough donors. Determining potential recipients begins with the second principle, "to each according to need," as defined by match and medical urgency, with recipients placed on a waiting list based on degree of urgency. Unless urgency changes, each candidate advances up the waiting list according to his or her time spent on the list, and thus each has an equal chance of obtaining a matching donor heart, consistent with the first principle, "to each an equal share." Effort, contribution, merit, and free-market exchange play no real part in the organ-matching process.[10]

Although the aforementioned principles underlie the formal basis for most theories of distributive justice, recent writings present other perspectives for consideration. These theories generate some interesting questions about the distribution of limited healthcare resources. Because they are not universally accepted, they offer an opportunity for further discussion and debate.

Daniels[9(p 235)] has written extensively about a concept he calls "fair equality of opportunity." He is concerned about the undeserved advantageous and disadvantageous circumstances from which persons may receive social benefits. These include properties acquired by social and biologic lotteries for which the person is not responsible. For example, an individual with cerebral palsy cannot be considered responsible for his or her functional disabilities or the necessary healthcare. Under such circumstances, the fair opportunity rule would state that society needs to provide healthcare services that ameliorate the symptoms of his or her condition, thus creating what Daniels calls a fair opportunity to participate in and enjoy life.[9]

More controversial is the concept of age-based rationing, which proposes limiting healthcare services for persons within specific age-groups, or giving them lower priority, particularly the elderly. It is argued that age is different from race or gender inasmuch as age-groups represent a developmental stage in every person's life. Age has been used in some countries to limit services (eg, the United Kingdom excludes the elderly from receiving dialysis and kidney transplants). Although age-based rationing presents difficult moral, political, and practical dilemmas, it is likely that the issue of age and its relationship to limitation of healthcare resources will continue to be reviewed, particularly as the Baby Boom generation ages.[9]

Another concern often raised in discussions about the distribution of scarce resources relates to the right of individuals to receive services for health problems that are a direct consequence of their own voluntary actions. In some select circumstances, this may be appropriate. It is morally acceptable for transplant committees to consider patient compliance as a factor when determining candidacy for transplantation. As an overarching concept, however, it presents a number of moral questions. How does one discern what part of a patient's disease is caused by voluntary behavior and what part results from other factors? How truly voluntary are the behaviors? How would such a practice be monitored? Despite these difficulties, it is likely that individual responsibility will continue to be a factor considered in the distribution of healthcare services.[9]

• RECOMMENDATIONS

The Institute of Medicine's Committee on the Consequences of Uninsurance concluded their series of reports on insurance and healthcare by identifying 5 key principles for guiding policy development. Like others who have looked closely at the questions of fair and just access

to healthcare services, they recognized the first principle, universal access, as the most fundamental. The remaining 4 principles were given no specific priority. These guiding principles are as follows:

1. Healthcare coverage should be universal.
2. Healthcare coverage should be continuous.
3. Healthcare coverage should be affordable for individuals and families.
4. The health insurance strategy should be affordable and sustainable for society.
5. Health insurance should enhance health and well-being by promoting access to high-quality care that is effective, efficient, safe, timely, patient-centered, and equitable.[11]

Emanuel[3] suggested the use of 4 principles in the just allocation of healthcare resources. Although broad in scope and not substantive in nature, these principles can provide guidance as policies and practices are established for allocating limited healthcare resources.

First, the primary goal in making allocation decisions should be to improve people's health. Second, patients should be properly informed of the allocation and its justification. Third, whether in a managed-care organization or within a legitimate democracy, people should have the opportunity to consent to allocation decisions that affect them. Fourth, and finally, those making allocation decisions should minimize conflicts of interest. Emanuel[3] specifically addressed allocation decisions within managed-care organizations, but he stated that these basic principles are critical to just allocation of healthcare resources in any arena.

• CONCLUSION

Questions of just and fair access to appropriate healthcare services as well as just and fair allocation of limited healthcare resources exist throughout all levels of healthcare organizations. Despite the pervasiveness of these questions, healthcare professionals often go about their day-to-day work without thinking much about them or even recognizing their impact on patients and families. By raising the issues, this article may begin conversations about these problems, but finding solutions that honor the principle of justice is much more difficult. Healthcare providers, particularly those who are US citizens, must continue to look closely at how healthcare services are provided to all people, consider what can be done to ensure universal access to appropriate healthcare services, and think about just and fair approaches to allocating healthcare resources.

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