

## *Social Class and Medical Decisionmaking: A Neglected Topic in Bioethics*

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As part of an effort to look at “what differences make a difference” for bioethicists interested in clinical decisionmaking, Erik Parens, the editor of this special section, asked us to look at social class. When we began our research for this paper, we were surprised to find that although bioethicists have written much on social class and such macrolevel issues as access to healthcare and the distribution of scarce resources, and have paid some attention to the effects of class on patient-provider relationships, bioethicists have written little specifically that looks at the implications of social class for medical decisions in individual cases.

The neglect of this topic is unfortunate because there are a number of ways in which social class can “make a difference” for medical decisions that are of relevance for bioethicists. First, there are tangible differences in the living conditions of people of different classes leading to differences in health status and in the health services and other resources available to prevent or treat health problems. Second, even when resources are theoretically available, people of different classes may receive differential treatment from providers for the same health conditions due to discrimination on the basis of class. Most bioethicists are aware of these two spheres and see such differences as regrettable. They believe that there should be changes in social conditions and in the delivery of health services to reduce or eliminate such differences, yet there has been little in-depth discussion of the implications of such differences for medical decisions.

In addition, there is a third sphere that has received virtually no attention. Because of the differences in their lived experiences, people of different social classes have differences in values relevant to medical decisionmaking. Recently, bioethicists have become much more aware of issues of diversity, in general, and have begun discussing the implications of differences associated with gender, race, religion, and ethnicity. Some bioethicists have called for attention to issues of social class, along with those of race and gender. However, very little work has been done to spell out the relationships between the knowledge and power people experience in different class positions and the ethical values they apply when they enter the realm of biomedicine.

The purpose of this paper is to draw attention to the need for bioethicists to pay more attention to issues of social class when examining medical decisions

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and to begin a dialogue on the subject. While we will briefly discuss the first two spheres, we will concentrate on the third sphere since it is fairly new to bioethics. This paper draws on the experiences each of us has had as medical anthropologists. Betty Wolder Levin has been studying bioethical issues for many years, primarily concerning decisionmaking about treatment for critically ill children; Nina Glick Schiller has studied the needs of persons with HIV as well as issues of ethnicity, race, and class in multiple settings.

We start our paper with two vignettes, presenting extreme differences, in order to illustrate ways in which class “can make a difference.” We next discuss the concept of social class, explaining how it shapes peoples’ lived realities. We briefly review some of the bioethics literature pertaining to social class, highlighting topics discussed and topics absent. Then, we present additional vignettes to further illustrate how attention to class can broaden and complicate the discussion of end-of-life decisionmaking. We end with conclusions about class and medical decisionmaking and raise issues for further discussion.

### **An Introduction to Social Class**

To begin to explore the parameter of social class, we offer a vignette we constructed about “Martin,” the CEO of a growing Internet company:

Although his health had been failing rapidly, because Martin could keep in touch with his office from hospital or home, he was able to keep working, earning his usual income, in the weeks before and after his heart transplant. Other than his critical heart condition, his health was good, aided by his healthy life-style. He gave up smoking in the seventies as he became aware of the health risks. Until he became too sick, he exercised daily at his sports club or swam in his pool.

His ample catastrophic health insurance policy covered the costs of the transplant, the drugs to prevent rejection, and other follow-up care. Even his multi-million dollar a year salary did not make it possible for him to buy a heart (the way wealthy people in some places might be able to buy a kidney), but he could travel easily and his financial resources and his social network enabled him to seek the best of care.

As his health deteriorated, he talked to his college roommate from Harvard, a world famous neurosurgeon, as well as his doctor, a leading internist at a major teaching hospital, with whom Martin played golf every Wednesday. These two good friends helped him understand his condition and decide that his prognosis had become so poor that the benefits of a transplant out-weighed the immediate risk of death and the long term burdens of the therapy necessary to prevent rejection. They also helped him to evaluate the statistics of all of the region’s transplant programs—time on the waiting list, outcome statistics, etc.—and arranged for consultations with the three top transplant surgeons in the Metropolis area.

His wife, an interior decorator, took a hiatus from her job without seriously disturbing her career; her income was not needed for the family support anyway. Even though she was home, they hired nurses round the clock in addition to the usual domestic staff. The chauffeur was there to rush him to the hospital as soon as a heart became available, pick up the children at school, and later bring him for follow-up appointments.

Martin's situation is of course quite unusual. But many discussions of bio-ethical issues seem to assume a patient in circumstances like Martin's. That is, these discussions often assume that most people come to make choices about treatment based on medical benefits and burdens of treatment alone, without financial constraints or other priorities for their families complicating their decisions.

Unlike Martin, most people in the United States today cannot make such decisions without financial constraints and other class-related issues affecting their choice; class does often "make a difference" in how they think about their choices. This is illustrated by the second vignette. Although names have been changed, this is a real account, taken from outside the medical context. It is a passage from a book, *Coming Home: African Americans Reclaim the Rural South*, by anthropologist Carol Stack, which described the experiences of African Americans returning to the South. In this passage Eula has just returned to the South—to the land that her father Sam had been born on, first worked as a sharecropper, and then struggled for 50 years to own free and clear. Sam envisioned the land as a family compound, to which more of his many children, and the nieces and nephews, whom he and his wife Pearl raised, would return:

[Sam] fell ill right away, only a few months after Eula and Al came home. Doctors and medicine were no help at all. He would walk from his house across the yard to the trailer, and by the time he got there he was gray in the face and bent double. He'd be silent sometimes, uncharacteristically so, and they came to realize he was losing the strength to push words from his throat. But he had a lot to say, a number of warnings, long lists of instructions, and he made the time to say it all. To Eula in particular, and of course to Pearl, he explained the dangers of mortgages, the stratagems of land-hungry white people, the nuts and bolts from A to Z of keeping your own feet on your own ground.

One day he warned Eula he would have to kill himself. He didn't say it in so many words, for obvious reasons; rather, he spoke in a code that she didn't figure out until the next day. He called her on the phone to tell her not to worry about his illness. Don't worry about the doctor bills, he said, or the hospital. And don't worry about my suffering—I'll be all right. We know you will, she told him, surprised by the turn of his talk. He wasn't a man much given to doubting or to suffering doubters.

The next morning he shot himself, and Eula realized that he must have come to a decision before he called and was only trying to explain, not asking for sympathy or reassurance, only giving, as he had always given and always would. He was afraid his sickness would cost the family their land, afraid that medical bills would force them to sell off what he'd worked a lifetime to put together. He didn't want the land to wind up back in the hands of the white people and their damned banks. So he died to save it, and to warn the family to save it.<sup>1</sup>

### **Class as an Analytic Tool**

In this paper, we use the concept of class to provide an analytic tool that is useful for examining ways in which people's lives are configured by the historically developed social and economic structures within which they live.<sup>2</sup>

Studies of class in the United States, including those within the health services and healthcare policy literature, use as indicators of class either a form of social and economic status (SES) measure that assesses income, occupation, and social standing or simply yearly income. Most often all parameters of class experience are reduced to a measure of income, with class only raised as a relevant factor for those toward the bottom of the scale who are referred to as “the poor” or “the lower class.” Implicit in discussions of “the poor” is the assumption that most people are in “the middle class” and that all those above poverty level can be regarded as relatively uniform in life-style and values.

But to assess the significance of class differences, we need a concept of class that dwells not on relative ranking or comparative status but examines the different life experiences that people bring with them into the clinician’s office, the hospital ward, or the operating room. To do this we must set aside efforts to quantify social and economic status or income differentials along single dimensions and begin to examine the situated experiences that make up a person’s “life-path.”

For the purpose of this type of class analysis, we define class as a set of people whose position within the productive system is similar. This productive system consists of processes of production, distribution, and consumption that shape people’s lives. Thus the word *class* works as a shorthand to refer to a person’s social location, a “lived reality,” in which life chances, values, health and well-being, morbidity and mortality, and concepts of self, other, and collectivity are shaped by the relationship of the individual to the social organization of production.<sup>3</sup>

A person’s relationship to the productive system plays a significant role in determining the degree of power and resources she or he has. This relationship is not primarily a product of individual experience, effort, and luck despite the rags-to-riches myths that pervade the popular imagination. Inherited social position, family circumstances at birth and throughout life, coupled with the ascription of race, ethnicity, gender, and disability provide different degrees of access to resources, opportunities, and power as well as different ways of understanding the world. It is not class alone, but class as it is lived in relationship to other forms of social positioning such as race, ethnicity, gender, and disability, that leads to differences in social power. People of different racial ascription, ethnic backgrounds, or religious beliefs who are positioned in the same class, whether corporate managers or part-time cashiers, find that they have certain shared life-paths as well as domains of differentiation.

A shared life-path cannot be simply reduced to a neat set of common values. When clinicians do think about class, they often use stereotypes that project uniform values for all those who are unemployed or all those considered “professionals.” For example, many providers believe that professionals are unlikely to accept children with disabilities; some believe that those who are unemployed or on Medicaid are not concerned with confidentiality, since they don’t have to fear the loss of a job or medical insurance. Neither of these generalizations can withstand careful examination. This is not to say that those who share a class position are identical in their values and outlook—only that their values and outlook are shaped in similar ways by their shared experience.

We should note that while all persons begin life by inheriting class positions from their parents, the life-paths followed by persons in different class positions are not necessarily transmitted across generations. Class location is shaped

by the relationship of an individual to the productive system at a given point in time and to the way in which the system of production allocates access to wealth, power, resources, and privileges. Thus, both changes in the lives of individuals and changes in the organization of production, such as globalization and deindustrialization, that affect patterns and possibilities of employment or economic prosperity, change the life circumstances and therefore class-specific positions of members of that society. That is to say, an individual's class behavior, thoughts, and actions are subject to rapid change. This approach to class stresses its situational nature. Class locations do not generate deep patterns of behavior inevitably passed on from generation to generation. Rather, because class locations are responses to different possibilities, opportunities, daily life experiences, and necessities, they change.

The person who is a tenure-track anthropology or philosophy professor may earn about the same as a waitperson (formally known as a waiter or waitress) in an expensive, fashionable restaurant, but the professor and the waitperson have different life positions. This is true not because of education (the waitperson may be an unemployed academic) but because at least some of their activities, routines, daily companions, daily patterns of speaking and thinking, and understanding of how the world works will be different. The tenured academic may feel that success comes from merit while the unemployed academic who is now a waitperson may feel that success comes from luck and access to social and family networks.

Class is not necessarily a self-conscious identity; it may remain on the level of an analytical shorthand that summarizes a person's social positioning. That is, people who share common life-paths may not recognize each other as similarly situated. The unemployed manager who is now a part-time cashier may say he is middle class. The part-time cashier who has always been low paid may say she is poor. But if the manager goes through his savings, is forced to sell his house and rent an inexpensive apartment, no longer sees his old friends because he cannot afford their life-style, and turns in his leased Lexus for a used Buick, then both the newly made and life-long cashier will start to share life circumstances, and to a certain extent, point of view. But while class is not an identity, it is possible that political leaders and movements can claim to speak for those who share class positioning, and that those so positioned become conscious of their commonality and speak of themselves in the language of class. This has happened in the United States in the past but rarely happens now.

This conception of class means that it is possible to develop profiles of different class locations that tell us more than the comparative, relational words often used in the United States on the few occasions when stark differences in wealth or life-style push us to begin to think about class: rich and poor, upper, middle, and lower, white collar and blue. As a shorthand, it is sometimes necessary to refer to class as relative positioning. However, we wish at all times to stress the different lived realities of different class locations that reflect different relationships to the productive process.

The outcome of different class positions that results in differences in social power is apparent when we compare the two vignettes we introduced earlier. We began by sketching the hypothetical case of Martin, a white, Anglo-Saxon male. In part, Martin is shaped by his commanding position in the economy—not only his wealth, but also the confidence he gets from being the one in

charge and by being on equal footing with those in charge of other sectors of the society. His class location shapes not just how much money he has, but the way he lives his life: that he employs a wide range of people not only to work in his business, but also to help rear his children, to keep his house, and to care for him when he is sick. Family ties, expectations, and obligations are important indicators and also shapers of different class locations. If Martin has inherited wealth from parents, he may have semi-corporate relations with siblings or even more extended relatives, linked together through trust funds. If not, he can choose to strengthen or break relations with family members on the basis of whether they have common interests.

Sam, the African-American head of a rural household, was a real person of the contemporary U.S. South. To do what he felt was best for his family, Sam stayed away from the healthcare system, and therefore away from making a decision about modes of care for his debilitating illness, by taking his own life. His class location differs from Martin's not just because he was African American or had less income. His reaction to debilitating illness reflected his specific experience as a sharecropper, which shaped his belief that owning land would provide security and status for both himself and his family. His relationship to the productive process was linked to his sense of well-being, and his decisions about consumption, family, and finally life and death reflected the values his way of life had generated—values that made his ability to own land and pass it on to his descendants central to his life. Within this class location, extended family networks become not just a matter of choice, but a matter of both survival and a source of self-esteem.

Differences linked to class are likely to gain increasing importance again. After gains in social equality during the post World War II era, within the past decade, the United States, for example, has been rapidly changing because of the restructuring of the global economy. This restructuring is reflected in the changing profile of the distribution of wealth in the United States. This is illustrated by the fact that the wealthiest 1% of the population owned 19% of the private wealth in 1976, but 40% in 1995.<sup>4</sup> The growing disparity between rich and poor means that while for CEOs like Martin life has become increasingly privileged, most other people are working harder, earning less, and have a smaller safety net to sustain them in times of sickness or personal crisis. The wages of the bottom 80% have stagnated or declined since 1977 and increasing numbers of people find their relationship to the productive system peripheral as they are forced to depend on part-time, low-waged work. The context for this is the development of massive corporate profits through global production that results from the use of cheap, and very often politically repressed labor.

Part and parcel of the restructuring of capital has been the search for new arenas of profit through corporate downsizing and the privatizing of services that governments used to provide—support for the elderly and the unemployed, education, sanitation, public health measures, and health insurance. This restructuring means that it is even more imperative not to take Martin as the norm but to analyze the ways in which the reduction of social support and public services of all kinds creates life-paths that shape clinical decisionmaking. While in this paper we focus on social class and clinical decisionmaking in the United States, these issues need to be examined all over the world.

To further explicate this concept of class and how it can help put medical decisionmaking into the context of patients' lives, we will examine two other

vignettes, which are constructed from our field work, observations, and life experience. But first, we will comment on the lack of attention to social class issues in the bioethics literature.

### **Social Class in the Bioethics Literature**

To begin research for this paper, we conducted bibliographic searches of the medical literature using *Medline*, a service that includes citations from most of the major journals in the field of bioethics. We were surprised to find *no* citations when we searched for both “bioethics” and “social class,” as subject heading or text words. Moreover, searching further, we found that there were no entries that had both “bioethics” and “socioeconomic factors,” “income,” “stratification,” “SES,” “middle class,” or “wealthy” as subject headings or text words.

When we used the terms, “ethic,” “ethical,” “ethics,” and “medical ethics” combined with “social class” as subject headings and text words, we found seven entries. However, even in this set, none of the works cited directly examined clinical decisions and social class. Only one article focused on social class in the clinical setting.<sup>5</sup> This excellent article, by medical anthropologist Kate Brown, examined how class affects issues of confidentiality for women with HIV. One article reported on a research study to examine health services and patient characteristics.<sup>6</sup> Another with an international focus was a letter entitled “Ethics for rich nations only.”<sup>7</sup> Some articles referred to class when describing a patient group or a population surveyed. For example, one of the seven articles concerned the use of natural fertility planning for a “middle-lower economic group.”<sup>8</sup> Another reported results from a survey of attitudes of “middle-class Australians” about embryo research.<sup>9</sup> Neither of these articles presented a comparison with people from another class, nor was class, *per se*, a focus of the article.

Continued searches did reveal more articles with other combinations of terms. For example, “ethics, medical” as a subject heading and “ethics or ethical” as a text word, yielded 22 cites with “poverty” as a subject heading or a text word, but most of the articles dealt with such topics as the allocation of health resources, bioethics in developing countries, and the sale of human organs from live donors. Again, the articles did not deal with clinical decisionmaking.

To be sure that we weren’t missing a major portion of the literature, we called BIOETHICSLINE,<sup>10</sup> and asked the professionals who are expert in the use of their bioethics database to do a search for articles on social class and clinical decisionmaking. They generated a list of 36 citations under the heading “social class and physician-patient relationship.” A number of these cites did contain some discussion of issues concerning class and will be discussed below. But no article except the one by Kate Brown had social class and bioethical issues in a clinical setting as its main focus.

As introduced above, there are at least three main ways in which social class is relevant to clinical decisionmaking. The first is that there are tangible differences in the conditions of people of different classes, including differences in health status and in the health services and other resources available to prevent or treat health problems. We have a great deal of information on such differences based on worldwide public health and social science research. No matter what measures are used to study the association of social class and health

status, major differences in patterns of mortality and morbidity are correlated with class. For example, people with lower incomes have higher rates of both acute and chronic conditions and accidents; poorer people are also more likely to suffer from multiple conditions and have higher rates of disability.<sup>11</sup> Although these differences are greatest for the people with the lowest incomes, there is a gradient through the class spectrum.<sup>12</sup>

Access to health services and the type and quality of the healthcare services that are made available also vary by class. In general, in the United States people who do not have job-related benefits have less continuity of care and often receive care from family members and providers with access to fewer resources. In the new structure of health services delivery, not only people without benefits, but also those with benefits in many managed care environments, face problems accessing needed services. Not only do people with lower incomes have less money available to spend on healthcare, but those with jobs that provide poorer benefits have fewer services paid for by their health insurance plans, and therefore need to spend a much larger proportion of their disposable income on healthcare. Unlike people with adequate wages, people who are unemployed or have very low incomes must often be concerned with acquiring the basic necessities of life, such as food and shelter for themselves and their children; often they need to make acquiring such necessities their highest priorities, sacrificing other health-promoting behaviors, including medical examinations.

Moreover, the healthcare system has traditionally been structured to provide the best coverage for acute, in-hospital care. This has a disproportionate effect on those of lower social class, because they are likely to have increased need for preventive, chronic, and long-term care. Other, nonfinancial barriers related to the organization of health services also affect utilization by people of different classes. These include the location and hours of health services, ease of transportation, amount of paperwork, and waiting time, both to schedule appointments and during medical visits. Time considerations affect persons in different class locations in dramatically different ways. For example, those who work in rigidly structured settings may have problems taking time off from work to go to medical appointments. If they take time off to go to the doctor they often lose income from hourly wages and may even lose their jobs.

Further, class positioning affects a person's relationship to medical providers, even if that person has adequate medical benefits and sick leave. Persons who are manual workers or clerks may experience their relationship with their healthcare providers as yet another situation in which they are in a subordinate position. Professionals expect to be treated as equals by their doctors and demand explanations and a high quality of care. Persons who are poor and/or black may distrust health institutions because of past abuses, including histories of human experimentation.

Social class differences are also associated with many differences in life circumstances that affect care of the sick. For example, poorer people are often more stressed not only by their own health and social problems but also by those of friends, relatives, and others in their social networks.

Bioethicists are aware of such differences. There is a substantial literature concerning the need to address issues of access to healthcare in order to address such disparities. For example, Annette Dula and Sara Goering's book, *It Just Ain't Fair: The Ethics of Health Care for African Americans*, has a number of

chapters that address both differentials in health status and differentials in health services related to class as well as race.<sup>13</sup> Arthur Caplan discussed issues concerning the allocation of scarce resources in his book, *If I Were a Rich Man Could I Buy a Pancreas?*<sup>14</sup>

In addition, some bioethicists have written about the ways that such differences can affect a person's ability to make medical decisions. Writing about the doctrine of informed consent, Ahronheim, Moreno, and Zuckerman state:

A poor person, for example, cannot be "self determining" in a health care system that denies access to care or adequate rehabilitative services. When that person is worried that what few assets she has will be eaten up by an expensive hospital stay, this will surely enter into her decision-making and compromise her ability to be truly autonomous.<sup>15</sup>

However, although bioethicists see the importance of the disparities, there is relatively little in-depth discussion specifically addressing the implications of disparities for medical decisions.

Second, even when resources are theoretically available, people of different classes may receive differential treatment due to providers' assumptions based on class. Recently, bioethicists have begun to pay more attention to the importance of providers' social attitudes. Particularly in the feminist bioethics literature and work on bioethics consultation, there has been a call for attention to factors such as "race" and "class" as well as "gender" not only for provider-patient encounters but also in the context of applied bioethics. Tia Powell, in an article about the case of a poor, African-American woman with fundamentalist religious beliefs, states:

Bioethics consultations cannot be understood as only the abstract weighing of competing philosophical principles. Rather, consultation is shaped by a particular context, wherein individuals' choices are affected by societal prejudices and beliefs regarding race, religion, gender, power, and social class.<sup>16</sup>

However, in this article, as in virtually all of the other articles calling for attention to social prejudices, although social class is mentioned, virtually all of the in-depth discussion concerns other social factors; class is not a main focus.

Both bioethicists and others who have called for attention to the way that many social factors, particularly class, affect clinical decisions generally have seen differences associated with such factors as inappropriate. For example, Schwartz and Griffin wrote:

Although most doctors, and patients, believe that medical judgment should be based solely on what is "best" for the particular patient, research suggests that extraneous variables such as patient personality, social class, and the like can also affect medical judgments.<sup>17</sup>

The usual assumption is that such differences are "extraneous" and interfere with what is "best" for patients.

However, as we discuss above, class position creates real differences in experiences that lead to differences in values. In addition to the first set of issues related to macrolevel differences in health status and the healthcare system,

and the second set of issues related to provider attitudes, there is a third way in which class can affect medical decisions. Like religion and ethnicity, class can lead to differences in what matters to patients, and therefore class is not always “extraneous,” but may be essential for understanding what is “best” for patients.

There is some work in the field of bioethics that recognizes the relevance of class in the third sense. Much of it is in the feminist bioethics literature on reproduction, in particular in work examining decisionmaking about childbearing by HIV-positive women and decisionmaking following prenatal diagnosis. For example, Dorothy Roberts, in her chapter in *Feminism and Bioethics: Beyond Reproduction*,<sup>18</sup> talks about the need to recognize the influence of class on the perspectives of patients. She cites a passage by Rayna Rapp, a medical anthropologist who studied the cultural meaning of prenatal diagnosis and reported that class differences shaped the way in which people talked about decisions to terminate a pregnancy:

One professional couple told [a genetic counselor], “If he can’t grow up to have a shot at becoming the President, we don’t want him.” A low-income family said of the same condition, “A baby will have to face so many problems in this world, it isn’t fair to add this one to the burdens he’ll have.”<sup>19</sup>

Most of the literature that does call attention to the relationship between a patient’s values and his or her class position focuses on “the poor.” Here the literature on values and class parallels the widespread tendency to limit investigation of the relevance of social categories to subordinated sectors of the population who are defined as different from the mainstream in behavior or in socially valued norms. As Laura M. Purdy notes in a footnote in her introduction to *Reproducing Persons: Issues in Feminist Bioethics*:

Just as race is not something predicated only of people of color, class is not only what the poor have, and sexual orientation is not just what homosexuals have.<sup>20</sup>

### **Social Class as a Context for Medical Decisionmaking: Some Illustrations**

To illustrate the manner in which social class must be understood as ever-present in the context of medical decisions, we will present two additional hypothetical vignettes. Arlene, like Martin and Sam discussed above, suffered from severe heart disease. Please recall, Martin didn’t have to consider economics, but could focus exclusively on the medical benefits and burdens of treatment. Sam opted out of clinical care entirely. Arlene was struggling with a complex set of medical and social considerations.

Because of her heart disease, Arlene had to leave her job as an office manager in a small stationery company in Poughkeepsie, New York. She was divorced, with one married son in town; her two daughters were away at school. Luckily, years ago, she took out a disability policy but it only provided her with half her previous income. Recently, she had to dip into her modest savings to meet expenses and had to stop giving money to her older daughter, a law student, attending

school in another city. While she was able to put her first two children through state universities without loans, her youngest daughter was forced to take out loans for college. After the onset of her illness Arlene could no longer keep house, drive, shop, or do the laundry. Her son did the grocery shopping but Arlene felt that his purchases cost too much; the friction increased her stress. Her daughter-in-law tried to stop in several times a week to help out with the housework, but she was employed and had a great deal to do caring for her two young children.

Arlene's children urged her to accept her doctor's recommendation to get on a waiting list for a heart transplant. Her doctor had been caring for her for years as her condition deteriorated; without a transplant he said that her life expectancy would be severely reduced and her quality of life, already poor, would be increasingly limited. However, she kept hoping she would be able to manage without it and her many worries kept her from taking that step.

When she was working she opted for the least expensive health plan so she would have the money to help her children get through school; as a result, she feared she would have to take out a second mortgage on her home just to pay the 20% co-payment for her transplant. And even if her health insurance paid for most of the transplant expenses, it would bring her close to her life-time cap; her follow-up care for another serious illness could leave her without any coverage at all. Even if she were to be able to return to work after the transplant, she feared that the costs of drugs would keep her from saving the money she planned to live on when she retired. And how would she pay a second mortgage? She had always thought she would be able to leave something for her children and grandchildren; she never thought she would be dependent on them.

She also worried about the logistic problems associated with the transplant. Her sister said she could come and stay with her in Pittsburgh; her niece is a nurse at the hospital there and strongly recommends the program. But how long would it be before a heart would be available? She wondered if she should go to New York to have the transplant, closer to home, but still almost three hours away. How often would she need to go before and after the transplant? Even a brief appointment would take a whole day, and if her daughter-in-law took off many more days from work, she would lose her job. She worried about who would take care of her during the recovery period.

On the other hand, if Arlene didn't go for the transplant, she didn't know what she would do. She was able to do less and less every day. Either way, she would need care. She didn't want to move in with her son; she said it wouldn't be right to disrupt his family. Her older daughter said she would leave school, but Arlene didn't want her to interrupt her training. Besides, if her daughter dropped out, she would have to start paying her law school loans in six months. And how long would Arlene need care? No one thought the little one should have to leave college.

Unlike Martin, Arlene couldn't deal with her treatment choice without also weighing the economic and social implications for herself and her family; both short- and long-term, her choices affect her future and the futures of her children and grandchildren. She would get help from her family, but as is usual for someone in her class position, she puts a strong value on preserving individual

nuclear family households and on “leaving something for the children and grandchildren.”

The final vignette illustrates a different class-based series of concerns for Tracy, a young woman with HIV, and her mother, Gloria, who worked in a factory.

When Tracy was 17 she left her home to live with her boyfriend. Five years later, weighing only 90 pounds, she was admitted to the ICU with PCP. For two weeks it was not clear whether Tracy would live. In the teaching hospital in Newark where Tracy was hospitalized, she was treated with state of the art, aggressive care. The residents and the supervising attending physicians made all the treatment decisions. No one raised questions with her or with her family about the aggressiveness of care during this or the three other hospitalizations for opportunistic infections that she had during the year following diagnosis.

During her initial hospitalization Tracy’s 6 month old and 4 year old went to live with her mother Gloria in the dilapidated old house that Gloria had just purchased. After a month, Tracy’s doctors concluded that she could be discharged but needed constant care. During the hospitalization, Tracy’s boyfriend, who was also HIV infected, disappeared. The discharge planner thought Tracy would be eligible for the New Jersey program of managed home care—but believed it could only be provided if there was a full time care giver to live with the patient. The program provided AZT and home visits from nurses, social workers and physical therapists. It did not provide for day to day needs (Tracy was having trouble walking and needed help even going to the toilet). Tracy was discharged to Gloria’s house.

The implications of discharge to her mother’s house for Tracy’s overall well being, and the health and well being of her children and extended family, were never considered. Every few days health care providers—nurses, social workers, and therapists provided by the New Jersey AIDS program—would come to the house with expensive medications or provide advice or check on Tracy’s weight and vital signs. However, Tracy’s mother’s care was taken for granted by the formal health care system. For her part Tracy felt that she had no choice but to live with her mother, and Gloria felt she had no choice but to take her in. This decision resulted both from the economic necessities and both women’s expectations about what families do in such circumstances.

Gloria was already taking care of the three children of another daughter who had died from hepatitis. Up until Tracy’s discharge, Gloria had managed to keep her job at a factory, which paid for day care and the mortgage, and provided a little extra to supplement the AFDC payments she received for the support of her three grandchildren. But after Tracy’s illness—faced with five grandchildren and the need to care for Tracy, Gloria was forced to quit her job and apply for welfare. Tracy was eligible for SSI, but no check arrived for an entire year.

The welfare payments barely provided money for the mortgage; with the other bills it became harder and harder to make payments and it looked like Gloria would lose the house that had represented a life long dream and sheltered her expanded household. The furnace was old and Gloria did not see where she would get the money for fuel oil. Tracy had no clothes that fit her now that she had lost weight. She had to use money that was needed for basic necessities to take a taxi to the hospital for her HIV clinic visits. Although there was a van

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provided by a special transportation program, she had to wait for hours for the van which sometimes didn't arrive at all which meant she missed her appointments. The hospital was too far to walk—even if Tracy had been able to walk. She wet the mattress and there was no money to replace it or to buy sheets. There was no money for the laundry for Tracy and for the five children. Tracy's needs meant that there was very little money for the children's clothing, diapers, and other needs. Both Tracy and her mother seethed with rage which they vented on each other, when Tracy had the breath to talk or Gloria had the time.<sup>21</sup>

There were different bioethical concerns in the cases of Arlene and Tracy not only because of the difference in the nature of their illnesses and their ages, but also due to their class positions. To begin to investigate the factors that come to play in the arena of medical decisions because of the class positioning of patients, we must see Arlene not as representing all of the middle class but as occupying a particular location in relationship to production. That is the "location" of having had a steady job with a moderate level of benefits, some sense of autonomy within a workplace routine, and some level of formal training. Persons in such a position often strongly value autonomy and education. Their households may well be nuclear, although they often have kin who live close enough to be able to provide a certain degree of ongoing support and mutual assistance. These kin may have enough resources to help with short-term emergencies but can't provide long-term solutions. We know from our own life experiences that there are other ways of being middle class—and that each of these leads to variations in family support systems, in access to medical care, and in the ways in which medical decisions are approached and understood.

Similarly Tracy, a patient with HIV, and her mother Gloria, who felt she must quit her job in a plastics factory to care for Tracy and her children, cannot simply be glossed as poor or as blue collar. Gloria's type of job gave her years of full-time employment with benefits, but as factory work this employment had often required work at night or on the swing shift; it also had periodically been disrupted by layoffs and plant reorganizations. It was a job that provided less social status than Arlene's but about equal benefits. It also provided for even less autonomy in the workplace, required less formal training, took greater tolls on her body, and structured for her different rhythms of daily life that affected family routines. All of these life experiences shaped an ethic of work and family that persons in class positions such as Gloria bring to bear on clinical decisions for both themselves and their families.

Tracy, although a 22-year-old single woman with AIDS, was not an isolated individual but a part of a family.<sup>22</sup> Gloria saw the decisions about Tracy's care as relevant to the collectivity of family, while the clinicians treated only the individual patient. The physicians who treated Tracy made decisions about ICU admission, resuscitation, and discharge thinking only of Tracy at the moment of her medical crisis. Their domain for ethical consideration did not include responsibility for the effects of their acts on her mother, her children, or her nieces or nephews.

In addition to class, in many instances, patients' values and priorities reflect differences that come from a set of social positions, including ethnic or racial backgrounds, religion, gender, and age, as well as class. For example, in addition to her other fears, Arlene, as an African-American woman, was reluctant to

place her life in the hands of an unknown medical system in a distant hospital, afraid that she would not receive the quality of care and respect accorded whites. Her white doctor did not understand her hesitations in this respect. For both Gloria and Tracy, it was inconceivable that a 22-year-old mother of two would choose to forgo treatment; no one in their big Italian family had ever questioned the aggressiveness of life support. They believed in the power of God and prayed for a miracle.

## Discussion

In this paper, we have taken a preliminary look at how social class “makes a difference” of relevance for medical decisions. We conclude that there are a number of ways in which it should be considered by clinicians, bioethicists, and others interested in medical decisionmaking.

First, it is important to understand differences that often exist in the health status of persons in a variety of class positions and their varying access to health services. This means not only considering the relationship of poverty to health, although that certainly remains a pressing need. It also means it is necessary to remember that *all* persons have a class status, not only the poor, and that one must consider the class position of all people to understand health status and the use of health services. It is also important for both bioethicists and healthcare providers to be sensitive to the ways that provider attitudes about people of different classes affect treatment. Moreover, it is important to understand differences in class-based concerns that patients bring to medical decisions. Like awareness of cultural differences stemming from ethnic diversity, it is important that clinicians be aware of the importance of class position for such issues as who is defined as family, how resources are allocated, and how health is defined.

As a result of these underlying differences, it is important to recognize that giving people the same choices about medical treatments does not necessarily mean that they are being treated equally, because patients do not lead equal lives. Different amounts of resources, access to power, and social positioning lead to very different life possibilities and realities. Both Martin and Arlene may obtain places on heart transplant lists, but choosing to have the heart transplant would not have the same meaning for each patient. Moreover, for all of the cases presented in our vignettes, choosing the option of life-sustaining medical treatment has major ramifications, not only for the patients but also for their families, in ways that matter to the patients.

But what are the implications of recognizing such differences? For the past 25 years, there has been much discussion of when it makes sense to limit aggressive treatment to avoid prolonging the lives of some critically ill patients. Primarily, the discussion has focused on situations where the prognosis, as defined by medical criteria, leads to questions about treatment for those whose medical conditions are seen to lead to a quality of life so poor that aggressive treatment does not justify its burdens. Here, we have discussed differences by social class that lead to differences in quality of life for the patients and their families. We must acknowledge differences in life experiences, concerns, and ramifications. Yet clearly we shouldn't say heart transplants are only justified for CEOs like Martin, and that Sam's solution is the one we advocate.

Recognizing these differences presents difficult challenges for bioethicists on a number of levels. First, on the level of clinical decisionmaking, some people may attempt to use differences in quality of life associated with social class to justify unfair, differential treatment. When judgments made by providers lead to the denial of services, the appropriate response for bioethicists is not problematic. They must identify the nature of such decisions and fight such discriminatory practices. Bioethicists face more complex questions, however, when patients or family members make decisions to forgo medically appropriate treatments as a result of class-related considerations. As with decisions to forgo treatment by people with impairments who suffer from a poor quality of life because needed services are not available and because they are handicapped by discriminatory attitudes,<sup>23</sup> decisionmaking by patients and family members who suffer because of class-based inequities presents a challenge. In the clinical context, how can one resist accepting the inequities yet at the same time respect patient and family decisions? To what extent can bioethicists “make a difference” on an individual level?

If clinical bioethicists are obligated to look at how class makes a difference, aren't they also obligated to look beyond medical decisions to the broader realities of their patients' lives and work to ameliorate the conditions that constrict patient choices? As we have demonstrated in this paper, many of the class-based factors that affect patients' health and medical decisions go far beyond issues of access to specific services and other problems that can be addressed on an individual level. Efforts to change the context of clinical decisions cannot be separated from broader social justice agendas. Medical decisionmaking is one of the domains in which the implications of the glaring inequalities in many aspects of peoples' lives are most dramatic. At the point of decisionmaking it becomes clear that class-based differences can even lead to difference between life and death. And the extent and the implications of these inequalities are now growing greater as a result of global restructuring, deregulation, and the dismantling of public services. Bioethicists concerned about equity in the clinical setting must clearly look beyond the clinic. Both in their roles as bioethical consultants, working directly with patients and practitioners facing life-and-death decisions, and while developing public policy, bioethicists are in a unique position to draw attention to class-based inequities. We must address the question: How can and should bioethicists, acting individually and collectively, respond to class differences by working to make a difference about class differences that make a difference?

## Notes

1. Stack C. *Call to Home: African Americans Reclaim the Rural South*. New York: Basic Books, 1996: 8-9.
2. The concept of class we explore in this article draws on the Marxist analysis of class, with its focus on the extraction of surplus value at the point of production, and Weber's concept of status group, with its emphasis on consumption, but differs from both these classic theorists. In anthropology we have been influenced by the work of the Lynds in their classic ethnography *Middletown*. (Lynd RS, Lynd HM. New York: Harcourt Brace, 1929). We are perhaps closest to Pierre Bourdieu's concept of “habitus” but our invocation of lived experience, positioning, and life-path is designed to emphasize change over time. See, for example, Bourdieu P. *Distinctions: A Social Critique of the Judgement of Taste*. Cambridge, Massachusetts: Harvard University Press, 1984.

3. For a very useful effort to develop a concept of class within the health literature, see Johnson JV, Hall EM. Class, work, and health. In: Amick BC, Levine S, Tarlow AR, Walsh DC, eds. *Society & Health*. New York: Oxford University Press, 1995:247-71.
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17. Schwartz S, Griffin TG. *Medical Thinking: The Psychology of Medical Judgment and Decision Making*. New York: Springer-Verlag, 1986:216.
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19. See note 18, Roberts 1996:125, quoting Rapp R. Accounting for amniocentesis. In: Lindenbaum S, Lock M, eds. *Knowledge, Power and Practice: The Anthropology of Medicine and Everyday Life*. Berkeley: University of California Press, 1993:55-76.
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21. When Gloria had to quit her job, she entered the world of "public assistance" not because she was unwilling to work but because she had to provide care for both her severely ill daughter and two sets of grandchildren. Now that even the "benefits" of this precarious "safety net" are no longer seen as an entitlement in the United States but something earned by forced uncompensated work, the possibility of "Glorias" being able to maintain households that include kin with chronic disabling disease will be even less feasible.
22. See Glick Schiller N, Crystal S, Lewellen D. Risky business: the cultural construction of AIDS risk groups. *Social Science and Medicine* 1994;38:1337-46.
23. See Asch A. "Distracted by disability," pp. 77-87 in this issue.