“Ethical Decision-making with Distribution of Scarce Resources”
An Essay for the 2003 ADAP Educational Conference

Introduction

It is an honor to participate in this national education conference for AIDS Drug Assistance Program (ADAP) administrators. The focus of this essay is ethical decisions for allocation of scarce resources. The guiding question is, considering the dramatic cuts in funding for AIDS programs, how does one distribute fairly what is available? Fair distribution seems to be a blend of getting the most benefit out of dollars spent in terms of life years restored to HIV infected persons (a look at effectiveness of consequences), and justice (a look at human need and human dignity). I know you want to make sure that those who can benefit from medications will in fact receive and use the medications. However, if medication is not available or if there are insufficient funds to buy and distribute the medication, providing optimal care for everyone in need will be impossible. One is faced with the possibility of providing less than optimal care for all or providing maximum care for those who satisfy certain criteria. This later approach may mean that some clients are denied services.

As a clinician, it would be very difficult to tell a capable but needy recipient that would benefit from antiretroviral treatment (like HAART) that there is no help available for them or perhaps an even more difficult case would be when an individual has been funded but has now entered a phase of illness where the medication provides possible but doubtful assistance. Withdrawing medication could signal hopelessness for them. How can you conserve the medication for those who will benefit while not allowing these clients to sink into hopelessness which would steal away their final days or months of life? Withdrawing medication may seem like a death sentence and yet providing them medication means that someone who could benefit will not receive the opportunity to have medication. Also difficult but probably a more frequent scenario is where you know the medication could provide assistance but it is doubtful that the client will be able to follow the necessary administration regimen. In this latter case, if you provide medications, you have not only given medications where they will not be used effectively but have actually enhanced the possibility of drug resistant HIV and the early decline of the individual. This discussion will share ideas and principles that are helpful in making decisions in situations involving scarce resources. We will first share some summary points from some key articles then take a more foundational look at ethical decision making.
Literature Review

James Cochrane and Anne Baley report that, “If patients cease taking antiretrovirals, their health is likely to deteriorate as the HIV in their blood rebounds. In addition, they are also more likely to harbour drug-resistant strains of the virus that may then be transmitted to others and prejudice future treatment.” It would seem that there is a real need to treat only those capable of sustaining treatment. However, The New York State Commission on Ethics saw these difficult compliance issues as no reason to not treat, rather they saw this as a reason to provide education and support so clients would stay within the treatment protocol. According to the commission, obstacles are no excuse for not treating, that is, obstacles offer no ethical justification for denying care. Agencies and clinicians are called to find ways to overcome obstacles. One has to ask how realistic is this? It seems the client of medication assistance needs to be able to meet you at least part way. One has to be able to depend on them to take medications as prescribed and to meet appointments for physical assessments.

Health care providers have responsibilities to ensure resources are spent on those who will benefit from them and not be harmed by them. It’s not like the medication does no harm. Antiretrovirals have tremendous potential for good and have revolutionized the outlook for HIV infected persons, but misuse of the medications is dangerous. Do I dare say that with limited resources less capable clients may need to be supported with other services but declined HAART until they are able to actively participate in their treatment program? Every life is valuable and every individual deserving of respect, but does this mean that resources ought to be dispersed to meet the needs of all persons? The resources simply are not available. It seems some persons have to be declined. If so, there needs to be preset health-related criteria with no discrimination based on personal attributes. With limited ADAP funding and inadequate client participation to qualify for assistance would one’s ability to pay privately override the criteria? Would the potential for income allow clients access to the limited supply even though they are not a good candidate to sustain treatment intervention? If it is determined unsafe to provide retroviral therapy to persons unable to maintain a medication and testing regimen, having money to pay for the medication privately ought not to make a difference. One still must conserve available medications for those who can benefit and also not harm the person requesting medication, either themselves or through family and friends.

A few years ago we were talking about improved quality of care based on increased funding, the use of combination therapies, clearer standards and greater expertise among health care providers. Today we have the therapies, standards and expertise. The question is whether or not these can be streamlined to reduce costs so that we can retain the same quality of care with less funding. There are two aspects to this challenge. On the one hand, we will become more efficient with the use of money, cutting minimally effective services. On the other hand, it may be necessary to more carefully discern if individuals will benefit from the available programs so that medication does not become distributed but unused. An added benefit to careful screening of applicants is reduced potential for formation of drug resistant HIV and a rebound viral load when treatment is stopped.
According to Noting, et. al., even with previous levels of funding there was a problem with unequal access to therapies. Difficulties included: “the difficulties of designing treatment regimens for patients with complex socioeconomic and medical needs; barriers to appropriate care that stem from organizational structure, staff training, and policy; and pervasive problems of treatment maintenance.”

They propose eight principles of HIV Care: (1) Since knowledge of HIV status is the first step in gaining treatment, all providers and agencies have a public responsibility to promote counseling and testing, (2) “Every person with HIV should have access to basic health care services as well as to HIV specialists as needed.” (3) “Health care providers have an ethical obligation to inform every person with HIV about all potentially beneficial treatments.” (4) “Determining an HIV treatment plan should be a collaborative process. Patients have a responsibility to be active in shaping treatment decisions that fit their circumstances and to maintain regimens. Providers have a responsibility to work with patients to explore treatment options and to identify and reduce barriers to care.” (5) Providers are responsible for facilitating the most appropriate treatment plans with special populations like the retarded or mentally ill. (6) Every patient with HIV should have access to support services that will enhance readiness to begin and maintain the treatment regimen. (7) “No one should be denied access to HIV treatment because of membership in any group, HIV high risk behaviors, or past medication experience, [these are] factors that do not reliably predict the ability to maintain a new treatment regimen.” (8) “Physicians are responsible for considering HIV treatment decisions in light of the potential for both individual and public health risk from inadequate HIV therapy.”

Noting, et. al., report, “It was the view of the workgroup [Ethical Issues in Access to HIV Treatment Workgroup of The New York State AIDS Advisory Council: report November 5, 1997] that denying patients access to information about HAART or to the therapies themselves without making a diligent effort to enable patients to use these therapies constitutes an ethically unacceptable standard of care.” Agencies are left with the question of what constitutes a diligent effort. How much effort is sufficient? One has to ask if the commission would retain this position in today’s economic climate. Factors commonly identified in research as associated with “poor treatment maintenance are side effects, forgetfulness, lack of access to health care and medications, untreated alcohol and intravenous drug use, and inadequate integration of the treatment regimen into the patient’s lifestyle.” If highly potent expensive medications are to be used, it seems these issues need to have already been addressed and support services in place, adapted to the needs of the individual client, prior to and concurrent with medication therapies.

While providers have an ethical responsibility to address these issues to increase compliance, providers also have a serious and compelling responsibility to ensure that all available medications and funds for distribution are used efficiently. They have an even more compelling responsibility to ensure that harm is not done by the development of resistant strains of HIV. Resistant strains probably account for much of the recent increases in HIV deaths and serious illness in America. It seems to me, one must conclude that sometimes the most humane and ethical option is to say “no.”

In America we have scant tradition of telling a person their condition is no longer treatable for the sake of saving the medication for someone who can benefit from it. It is also painful to tell someone they do not qualify for ADAP, no matter what the reason. The
best would be setting up a situation in which the individual themselves would see that they do or do not qualify. In this way they would self-select. Unfortunately, when confronted with this kind of crisis most of us are not realistic in our self-assessment. We ought not to expect others to do what we cannot.

**Policies are extremely important gatekeepers.** They depersonalize acceptance and rejection of clients and set standards for agencies. Policies stand between general principles of ethical practices and specific decisions. If the policies are well developed the decision becomes whether or not the individual situation fits within the policy. In 1998, P. J. Maddox addressed the need for carefully developed policies when she wrote that “Policy makers and managers must reconcile the ideals of community service, trust, and professionalism that have long been associated with those who provide health care, in a world in which responsible financial performance is demanded.” They must consider their obligations (including financial obligations) to the organization, populations requiring care, and the health care system generally. Competent and effective leaders must be able to deal with a wide array of issues: social, political, economic and ethical as well as health-related concerns. Maddox identifies 3 assumptions of the public context for ethical decision making. They are: (1) “the provision of **care on the basis of health need** without regard to race, religion, gender sexual orientation, or ability to pay; (2) **equitable distribution of resources** while considering vulnerable groups (i.e., frail elderly, poor, disabled); (3) **respect for human rights**, including the right to autonomy, privacy, liberty and health while considering social justice.” From what I have been saying it seems administrators are constantly in the middle. But, managers are faced with a triangle of duties; organizational goals and policies, public expectations, and the needs of individuals. Without being completely sure why, I have placed individual needs at the top. However, there are times when organizational goals and policies must take priority for administers, and other times when one must focus on public concerns.

![Diagram](image)

In the ideal, all individuals would have equal access to scarce resources. Health care organizations would provide for each what they are entitled to. **Discovering what each is entitled to can be very difficult.** In cases where individual needs conflict with public interests and needs, clinical providers in an organization are likely to feel they must represent the interests and demands of the individual under their care. Policy-makers and managers must interpret and enforce organizational policies or rules governing the decision
to allocate or deny resources. The idea that one must make treatment decisions with consideration of available resources may be repugnant to some, but decisions must be made with respect to economic budgets within organizations just as much as in one's private life. Resources have been and will continue to be rationed. Every day one budgets, that is, rations one’s time. Every day busy people allocate the scarce resource of their time. Allocation decisions are inevitable. Resources will be rationed based on implicit or explicit desires and beliefs. I would encourage you to make explicit the criteria used by yourself and those you lead by the development of clear, effective policies. We have already noted the valuable role of policies in taking decisions away from individual preference to an objective standard. According to Maddox it is through effective policies and equitable application of policies that organizations are ethical, effective, and efficient.

One of the currently identified agency-wide difficulties concerns allocation of preventive dollars. Prevention funding is distributed by the government based on reported new cases showing a need for prevention. This initially sounds reasonable but if a program is effective in reducing new cases they loose financial support. Ineffective programs are, thus, potentially being rewarded by additional funds. As a basis for a fair distribution of goods and services, one needs to have identified outcomes and careful program evaluation toward meeting identified goals. Funds need to be tied not just to client needs in the service area but also agency effectiveness. Clearly, finances need to be used as effectively as possible.

In the area of individual clients, organizations need pre-established criteria; patients would place into a program as they met the criteria. If there are more qualified clients than funded placements the ethical decision might be to have a cue, a line as at the bank. Intersecting with sequential listing of clients waiting for care is the priority that needs to be given to a client in more acute need. The impact of illness acuity would also need to be established by policy. An alternative would be to provide everyone who qualifies with the percent of services equal to the new funding, say 80% of the ideal because we now have only 80% of the agency funding. This later alternative could be met by eliminating minimally helpful or less effective or less necessary interventions. While the funding would thus be decreased the impact of services need not decline.

Presently alterations in expected patient criteria and contributions are making it more difficult for individuals to qualify for government funded treatment programs. In the future, case workers may have to tell more people, "No, I am sorry, we cannot help you." This is very difficult and good sense tells us that these decisions must be generated by a standard set of criteria. We found with renal dialysis machines years ago that when deciding criteria were determined locally, those who qualified on the local level had personal attributes that mirrored those of the deciding committees.

Writing for the Canadian Medical Association Journal, McNeally and Dickens, specified seven guidelines that might be helpful at the clinical level. What follows is a summary statement of those items. (1) Choose interventions known to be beneficial on the basis of evidence. (2) Minimize the use of marginally effective tests or interventions. (3) Use the least expensive of the effective tests and treatments. (4) “Advocate for one’s own patients but avoid manipulating the system to gain unfair advantage…” (5) “Resolve conflicting claims for scarce resources justly, on the basis of morally relevant criteria such
as need (e.g., the patient’s risk of death or serious harm could be reduced by the treatment) and benefit (e.g., published evidence of effectiveness), using fair and publicly defensible procedures (ideally, incorporating public input).” (6) Be sensitive in the way patients are informed of cost constraints. Avoid blaming as this undermines care by reducing confidence and increasing anxiety. (7) Resolve unacceptable shortages at the agency and government level, not at the level of patient contact.xiii

**Principles and Decision-Making Strategies**

We now take a closer look at the ethical principles we have been referring to and some decision-making strategies. Philosophy claims very few answers as its own, primarily it is a way of looking at situations, a way of discerning answers within a context. Ethics can suggest principles and address the application of principles, but it requires someone willing to provide context for the application of these principles. **Ethical decision-making is the realization that this situation is a case of a particular principle,** be that just distribution of resources or the necessity of maintaining the organization in order to provide any client services. In the above discussion we have been using the principle of **Justice** as the distribution of resources based on need. Alternative criteria include equity, contribution and ability to pay, patient effort, and merit.xiv Each criterion has difficulties, but in health-care as in most of society **the greater human good is found in resolution of needs.**

**Autonomy** is also an important ethical principle. Some feel it is most important as it captures the essential human ideas of self-determination and respect for personal decisions. However, as in the work of Robert Veatch and Willard Gaylin, it must not be allowed to trump all other considerations. Autonomy must be balanced against Justice, Beneficence, and Nonmaleficence.xv **Nonmaleficence** is the minimal ethical standard of doing no harm, while **Beneficence** is the call to do the good that needs to be done. Some time ago Autonomy became the health-care slogan in opposition to Paternalistic Beneficence, the perspective that as clinician I know what is best for you. The client’s role was to acknowledge this superior perspective and to comply. **Autonomy pushed powerfully against this Paternalism to bring a sense of power and dignity to the individual in their self-determination.** However, the reality is that physicians, nurses and other health-care providers have been educated to know the best options in the vulnerable situations in which we find ourselves when in a state of ill health. The wise patient gives deference to the opinions of the experts. And, health care providers must not capitulate their professional role in the name of patient autonomy. **There needs to be mutual respect and a balance between the clinician’s expertise and the patient’s self-awareness and self-determination.**xvi

In his book, *The Basics of Bioethics*, 2nd ed., Veatch combines beneficence and nonmaleficence into an “overall measure of consequences called utility.”xvii **Social Utility** proposes that what ought to be done is what maximizes the net good. This is very hard to calculate especially where one would hope to quantify benefits like relief of pain or mental anguish. Veatch suggests there could be a unit that would permit comparison on a single scale interventions that extend life and those directed towards improving the quality of life. This unit would be called “quality-adjusted life-year (QALY).”xviii The QALY would allow for ranking of alternative interventions in terms of the amount of well-being or the number
of quality-adjusted life–years bought per unit of resource invested. Sounds good! Finally, a measure to solve questions of resource utilization that allows for mathematical comparisons, dollar for dollar. The morally correct course would be the one that maximizes the aggregate net benefit per unit of resources.\textsuperscript{xix} Except, \textbf{striving to maximize aggregate net social benefits is not sufficient.} Outcome measures can not ensure that benefits are evenly distributed. They do not take into consideration individual needs and the responsibility to meet fairly the needs of a population.

**Distributive Justice** can be seen as the balance between the principle of Justice and the consequences captured by the principles of Nonmaleficence and Beneficence. If one were to include Autonomy in this diagram where would it be? Would it be the fulcrum on which these hang? Or would it add weight to Justice? In thinking about this it seems that self determination and respect are part of personal dignity that leads to Justice. **ADAP Distributive Justice** would be the balance between personal dignity and need as compared to life years restored and the requirement of not causing harm.

With distribution of scarce resources, one is concerned immediately with distributive justice and utility, outcomes from possible treatment options. As noted earlier just distribution may be based upon need, contribution, or merit. Maddox and Veatch take ‘need’ as the parameter for distributive justice. In looking at human life and nature, we see that humans have capacities to learn and make decisions based on knowledge. While humans can surely act on unbridled feelings, and some individuals preserve this option as a personal right, it is the ability to discipline feelings and look to knowledge for guidance that generates ethical actions. Principle-based actions are uniquely human. Within nature outside of human life, actions are guided by principles that were generated within nature herself. Science works to uncover and even to bridle these principles and forces to preserve and enrich our world.

Human beings as natural must operate within these natural principles and forces. None of us can just jump from the window, put out our arms and fly. On the natural level we expect and are expected to comply with the demands of nature. While some of my students hold that speeding laws are for earning the state money, they actually are to prevent accidents and preserve the life and property of the driver and passengers. When entering a corner too fast natural centrifugal forces will pull the car off the road. Following on this, many contemporary young people want to be able to decide everything themselves, even how fast is too fast. They want to reject the posted speed limits set according to practical experience or as a result of engineering studies. In the same way, they want to reject the causal relations between health and behavior. People, not just young people, think they have an independent right to do whatever they want. They even think they stand in some way outside of the law of consequences. Then, whenever difficulties result from their choices, they are shocked and feel entitled to be taken care of. In other words, they do not connect choices and the responsibility to deal with consequences from their choices. There is a dis-connect between actions and consequences.

My concern is not where this perspective comes from but that we need to address individuals with this perspective in ways that are realistic, that is just, and caring. There is a tremendous task in education and in forming behavior towards healthy outcomes. **To**
care for another and express concern in an empathetic way is not judgmental but acknowledges personal accountability and calmly but firmly imposes the limits that exist.

Limits are real. Those who manage organizations must respect limits. We do not have unlimited resources. What all of this is saying is that as ADAP administrators, you are called to distribute resources with one eye on justice and another on social utility. Unfortunately, not all situations are as easily resolved as seeing that a particular individual fits within a particular agency policy drawn from the principles of justice and utility. Additional decision-making guidance is often required.

An especially clear account of decision-making methodology can be found within the ancient writings of Aristotle. He wrote the first book on ethics called the Nicomachean Ethics. He did not accept that one could just appeal to a principle as we have so often done in this paper. He certainly had a place for principles, but there are many situations that do not fit under a principle that would guide action. Additionally, principles need to be interpreted within situations. Thus, they provide guidance but tend to create difficulties when it is not clear which principle has the priority. One needs a method of prioritizing principles in order to resolve ethical dilemmas. A dilemma is when there are good reasons for doing two different but mutually exclusive things. The values by which one lives can be seen as setting priorities among principles. Some people give highest priority to personal freedom and thus make decisions principally on Autonomy. Some take human life as the highest value and make decisions on this value, and so on. The difficulty is that as health-care professionals we are called to be self-aware, and while respecting our own integrity, we are not to impose our values on those who come to us for care. The value decision must be made in the employment one accepts, not in discriminating among clients.

Aristotle taught that when faced with a situation that does not fit a particular accepted principle as expressed in policies, you would need to identify the extreme options, like not providing medications to anyone who missed an appointment or providing medications to everyone regardless of their compliance. Given the most generous of all worlds, what would be done? Given the stingiest of all worlds, what would be done? The goal is to discover the middle ground. This middle ground would be the best of all worlds.

Finding this middle ground is not simple and requires careful decision making. Aristotle might even say, a well developed habit of discerning the proper choice, wisdom. As part of this analysis you need knowledge about the situation and about potential options. It would be best to seek counsel from those that are well respected within the content area and have a reputation for good judgment. These persons have years of experience and a good grasp of effective actions. Aristotle would have called them wise. Part of being wise and making good decisions is to know yourself. If you tend to be stingy or fearful, the median decision will feel risky or overly generous. If you tend to be overly generous or fool hearty this middle ground will feel stingy and the choice of a fearful person. In knowing yourself, you can choose away from your tendencies knowing that you have made the moderate choice. These steps are quite helpful because life is rarely simple. (1) Discover the extremes and avoid them. (2) Consult with
knowledgeable, wise people to discover what they would do in the situation. (3) Know yourself and, finally, (4) choose away from your tendencies. In this you will find the median or moderate decision. Aristotle thought that by avoiding these extremes one is more likely to reach stable, happy, peaceful solutions.

The ancient philosophers valued knowledge. Knowledge allows one to have choices and to make good choices. Within your work with staff and clients much of your role is educator and mentor providing knowledge and guidance. You need wise counsel in order to provide wise counsel to others. In most difficult cases it takes much courage to follow-through on what you know is the right thing to do.

Within this essay we have sought knowledge from those who have studied ethics and ethical decisions in situations of scarce resources. Some of these have specifically addressed HIV services. We have sought to find a balance, a middle way, within identified ethical principles. We have also noted how ethical decisions may take different forms. One may see that a particular situation requires the application of a principle or a policy. One may use the major principles to evaluate policies. For the difficult cases one can seek the middle ground, the alternative solution and ultimately we must have wise counselors and be wise counselors.

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6. Noting, et al. p. 4 of 10. “Support strategies implemented within the HIV treatment setting might include teams of trained providers regularly repeating and reinforcing messages; forums; pill organizers; buddy systems; and other teaching aids....External support services include provision of housing, drug treatment, mental health programs, regular meals, cooking facilities, medication supplies and storage, health insurance, legal services, child care, flexible work schedules, and social service programs.”
8. Maddox, p. 3 of 8.
10. Maddox, p. 6 of 8.
12. “Some would argue that proportional allocation is fair, in that HIV-prevention dollars awarded per AIDS case are roughly the same across the states. We would argue, however, that state health departments should be rewarded for preventing new HIV infections as opposed to reporting AIDS cases.” (p. 2 of 5)