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The Key to Health System Sustainability

by Douglas K. Martin

Priority setting is arguably the most important health policy issue of our time. No health system, whether primarily publicly funded (e.g., the United Kingdom, Canada) or privately funded (e.g., the United States, Tanzania), can afford to provide every service



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it may wish to provide. Skyrocketing costs, particularly of new technologies including drugs, are challenging policymakers and administrators to maintain quality and control spending simultaneously. The sustainability of health systems everywhere is at risk.

Health system sustainability has been framed by politicians, abetted by journalists and others, as either an issue in efficiency or funding. That is, we can sustain the system by adding more resources through eliminating “waste” in the system or through increased government funding. Looking for more money is,

however, inherently unsustainable. The key to health system sustainability is priority setting — making difficult limit-setting decisions — and the key to priority setting in any pluralistic democracy is creating an environment in which limit-setting decisions are acceptable.

The unwillingness of health system leaders to say no, or to create the environment in which no is an acceptable response, has contributed to the sustainability problem in health systems (Ham and Coulter, 2001).

The Problem of Priority Setting

Priority setting, sometimes called resource allocation or rationing, involves the allocation of limited resources (e.g., money, clinicians’ time, beds, drugs) among competing choices (e.g., institutions, clinical programs, patients, diseases, services). It occurs simultaneously in multiple contexts at all levels of the health system — macro (e.g., governments), meso (e.g., regions or districts, hospitals), and micro (e.g., clinical programs) — and each level affects the others.

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Priority setting has become the moral issue in medicine today — the key to emergency preparedness and the sustainability of our system.

From the Contributing Editor

Deciding What Is Fair

Ethics in Disaster Planning

This issue of *Practical Bioethics* is about allocating scarce medical resources. Allocation, sometimes called “rationing” or “prioritizing,” much like triaging, refers to who gets “what” and “when,” when the capacity for “what” diminishes even as the desire and need for it increases. In healthcare, questions of allocation represent the biggest and most serious challenge. It is the moral issue for medicine, indeed for all present and future patients, in this century.

It is also overwhelmingly complex. But we have to start somewhere. One entry point into rationing’s labyrinth is through the ominous threat of a pandemic or other major disaster. Preparedness for catastrophic events, whether natural or resulting from human error or malice, forces us to consider our unexamined priorities and values. Another entry point is to



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examine the way priorities for who gets what are routinely set by decision makers in healthcare. This issue takes both ways of examining this challenge.

We all shout yes when it comes to enhancing healthcare quality, just as we declare a resounding nay when it comes to inefficiency and waste of resources. Yet the flesh-and-blood reality of clinical encounters and the institutional contexts in which they occur puts the profession of healing to the ultimate test. The tension between self and other is primordial. And in a societal ethos that underscores self-promotion, independence, and individual rights and freedoms, our healthcare systems remain ill-equipped to address the collision such tension inevitably generates. These essays demonstrate the ways in which this clash plays out in healthcare. With diminishing resources and escalating health needs and costs, how do we fairly resolve the intractable conflict between self-interest and the good of the group?

Yet, as our authors explore, what is “fair”? Whatever philosophical framework we choose to apply, such as, utilitarian, deontological, libertarian, or communitarian, we must still fashion reasonably persuasive arguments to support our methodology and position. What views of fairness can pass the test of sustained analysis and application to the multiple settings requiring fair distribution and rationing of medical resources?

To dodge this question would be an egregious sidestepping of our moral responsibility. As much as we avoid the “R” word, healthcare rationing occurs on multiple levels. When over 40 million Americans remain uninsured, when inequities persist among marginalized groups regarding health access, delivery, and outcomes, when the more affluent increasingly blur lines between what is medically necessary and what is personally desirable, when our health system’s escalating fragmentation cries for deep-seated reform, we can no longer afford to avoid the reality of rationing. Even when ethics committees deliberate about specific clinical decisions, resource allocation is the invisible elephant in the room.

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Rethinking Emergency Preparedness

Hospitals Plan for the Unthinkable

by Ruth Schukman-Dakota

Recent disasters, including the 1995 Tokyo Sarin release, the Murrah building bombing in Oklahoma City, the tsunami in the Indian Ocean, and, most recently, hurricane Katrina have healthcare organizations rethinking their approach to emergency preparedness. These disasters and the prospect of a pandemic illness raise many questions about healthcare's capability and capacity to respond



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to and care for all patients under potentially adverse conditions.

What are the rationing issues facing healthcare? Are there solutions that can be implemented? Do healthcare workers understand the legal and ethical dilemmas they will face if and when the number of patients requiring treatment and care significantly overwhelms the available resources?

Hospitals have, at least, a place to begin. The lessons learned from the hurricanes are not unique to hurricanes but ubiquitous across most disasters. As such, they can provide a focal point for reassessing healthcare's response to catastrophic disasters. Lessons learned include the following:

- Healthcare organizations have inadequate surge capacity.
- Communication strategies are usually the first to fail and are generally inadequate to integrate community resources that could be shared between hospitals and other response agencies.

• Supplies and equipment may be inadequate and ways to obtain more unavailable.

• Adequate numbers of staff will likely not be available.

• When a community's infrastructure fails, it may be unable to support its hospitals as it did before the disaster, so unless community hospitals have corporate support from outside the devastated area, they will struggle to survive and may, in some cases, fail.

Surge capacity is a healthcare system's ability to expand quickly beyond normal services to meet an increased demand for medical care.¹ Factors that affect a hospital's capability to surge include the number of staffed beds; staff availability; the availability of equipment, pharmaceuticals, vaccines and blood; and the capacity of laboratories to handle the increase in tests. Many hospitals are licensed for more beds than are actually available and are already struggling with staff shortages for day-to-day operations.

In 2002, the U.S. Medicine Institute for Health Studies hosted a forum titled "Surge Capacity – Is It Time to Move Beyond 'Just in Time'?" Participants made these comments:

There must be coordination between all levels of government and all players at the various levels. . . . There is an urgent need for candor and flexibility.

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When a community's infrastructure fails, it may be unable to support its hospitals as it did before the disaster.

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In a disaster, the goal is to maximize the lives saved with the understanding that the usual standards of health and medical care will be changed.

ibility in planning for surge capacity, and it is essential to determine just what we are planning for.²

In addition to working with traditional partners in disaster planning, for example, emergency management, public health, emergency medical services, and fire and law enforcement, healthcare organizations should also include the legal profession, risk managers, and ethicists when developing their disaster response and recovery plans. It is, however, the planning process that is critical, not the actual plan.

A recent study by the Center on Biosecurity at the University of Pittsburgh Medical Center brought together senior government officials, hospital leaders, clinicians, and public health officials to discuss hospital preparedness for a pandemic.³ Six critical challenges were identified and possible solutions discussed.

1. The concept of preparedness is not clearly defined. Current pandemic guidance needs to be reviewed and revised to clarify priorities and set specific surge capacity targets. The guidance should also specify measurable goals and identify essential

tasks, including tasks that require significant preplanning. Requirements and guidance should not conflict and should provide specificity and metrics.

2. Some preparedness efforts can't be resolved by individual hospitals. To optimize response capabilities, hospitals within a region should work together to develop plans for the consistent and ethical allocation of scarce resources. The process to identify and establish alternate care sites must be multidisciplinary and should standardize planning and response within the region. The plan should enable the sharing of assets and staff, a coordinated transfer of patients between hospitals and alternate care sites, and communications among hospitals. This regional hospital group should act as a liaison with public health and elected officials for medical issues, and communicate jointly with the public to ensure a consistent message. Another function of a regional committee would be to manage and deploy volunteers across all venues.

3. Demand for healthcare will exceed capacity. Local and national experts should be convened to provide guidance to healthcare organizations and communities regarding

- deferring services,
- admitting and discharge protocols,
- allocating resources,
- using resource-intensive care,
- defining care standards, and
- establishing alternate care sites.

4. Staffing will be inadequate. Protocols need to be established to allow staff to perform tasks outside their usual scope of practice. A consistent and efficient system for registering and activating medical and non-medical volunteers should be determined. Credentialing protocols should be consistent across the nation. Liability protection should be handled at the national level.

5. Funding is inadequate. Hospitals are struggling financially, and many are finding it difficult to allocate adequate resources to emergency planning and preparedness. Nationally, we need more realistic estimates of cost, increased and sustained federal funding, and a funding structure tied to achievement of goals.

6. Hospital solvency may be threatened. The federal government must develop coordinated, consistent, and timely mechanisms for reimbursement. To achieve this goal, the data needed for reimbursement must be identified and tied to routine recordkeeping within the healthcare systems.

Healthcare in New Orleans is still struggling to recover. Recent reports illustrate the long-term effects hurricane Katrina has had on the healthcare system. For at least

“Healthcare leadership should be at the forefront of the planning process.”

seven months the closest level one trauma center in Louisiana was 350 miles away in Shreveport. Other centers are available in neighboring states. The number of acute care hospitals decreased from sixteen to nine. Available beds are down from the pre-Katrina high of 4,000 to 2,000 currently. Part of the issue with increasing the number of beds is staff shortage. Even if more beds were available, the city simply lacks the personnel to staff them.⁴

There are many issues, even more questions, and minimal answers for healthcare organizations as they plan with their communities to define response to catastrophic disasters that could significantly impact their operations and solvency. Healthcare leadership should be at the forefront of the planning process. The goal is to maximize the number of lives saved with the understand-

ing that usual standards of health and medical care will be changed. Health and medical resources must be allocated fairly and in ways that are clinically sound. The criteria for allocation must also be transparent to the public and seen to be fair. To be successful, hospitals must be able to provide medical care for disaster victims while maintaining other essential medical services during and after a disaster.

Notes

1. Addressing Surge Capacity in a Mass Casualty Event, Bioterrorism and Health System Preparedness Issue Brief No. 9. AHRQ Publication No. 06-0027, January 2006. Agency for Healthcare Research and Quality, Rockville, MD.

2. *Surge Capacity: Is it Time to Move Beyond 'Just-in-Time'?* June 17, 2002. U.S. Medicine Institute for Health Studies. http://www.usminstitute.org/surge_summary.html Accessed April 3, 2007.

3. E. Toner, R. Waldhorn, B. Maldin, et al. 2006. "Hospital Preparedness for Pandemic Influenza." *Biosecurity and Bioterrorism: Biodefense Strategy, Practice, And Science* 4(2). Available at <http://www.biosecurity-journal.com/TONER.pdf> Accessed April 3, 2006.

4. B. Shute. 2006. *New Orleans's against-the-odds struggle to care for the infirm*. U.S. News and Report: Best Health April 24, 2006.

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Making Hard Choices . . .

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Priority setting is complex and difficult because, at its core, it involves choices between competing values. Policymakers find priority setting perplexing because they lack guidance on adjudicating between unresolved value-laden choices. Two examples illustrate: Should we fund a program that provides a large benefit to a few patients or one that provides a small benefit to many (Daniels 1994)? In a pandemic influenza crisis, should we give our limited stock of vaccines to the most productive, for example, healthy working adults, or to the most vulnerable, for example, children or seniors (Emmanuel and Werthheimer 2006)?

Health Technology Assessment is a traditional approach to priority setting. It uses the tools of evidence-based medicine to emphasize the benefits and values of evidence and cost-effectiveness analysis to emphasize the value of efficiency. But technology assessment provides only limited help to decision makers because it emphasizes only a narrow range of relevant values (Martin, Pater, and Singer 2001).

At the core, priority setting involves making complex choices among the full range of competing relevant values. Decision makers in many contexts have searched for the "simple solution" to their priority setting problems (e.g., evidence-based medicine and cost-effective analysis) but this search has failed (Holm 1998).

Theories of justice, such as utilitarianism, communitarianism, and libertarianism, provide a broader focus on the values that undergird priority setting, but such theories provide only limited help because they are too abstract to be directly applied or because in concrete situations they provide conflicting guidance, and we have no overarching moral theory to resolve these conflicts. Reasonable, intelligent people often disagree about these theories and lack consensus on how to resolve their differences. How, then, should decision makers proceed?

Fair Decision Making

Although we lack consensus on "what" priority setting decisions to make, we can agree on "how" to make them: fairly. Fairness is a key goal in any public policy setting and especially so in priority setting. Fairness means that priority setting decisions are made within a process that is morally acceptable, and perceived to be morally acceptable,

"Fairness is a key goal in any public policy setting and especially so in priority setting."

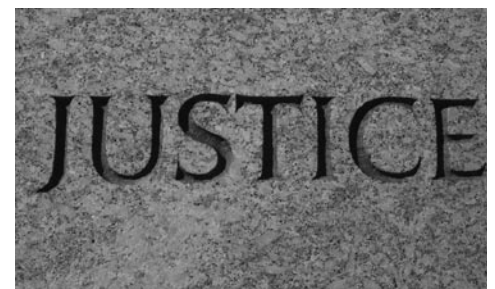
irrespective of outcome. Actually, it is more than that because a fair process includes checks that help ensure that unacceptable decisions are not made. But what is fair?

"Accountability for Reasonableness" is a framework for fair priority setting that provides practical guidance for leaders who want to ensure fairness in their priority setting context (Daniels 2000; Daniels and Sabin 2002). At its core are three principles that provide benchmarks for fairness: public engagement, publicity, and review.

Public Engagement

Health ministers, drug formulary committees, hospital CEOs, clinical leaders, and others can take direct action to improve

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But what is fair? Theories of justice provide only limited help.

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their priority setting through enhanced public engagement (Gibson, Martin and Singer 2004; Ham 1993). In one study, decision makers considered the inclusion of multiple stakeholders, including the public, as the single most important element to fair priority setting (Martin, Giacomini, and Singer 2002).

The public should be regarded as a key stakeholder for two reasons. First, any health system exists to serve the public. Priority setting decisions in the health system directly affect all members of the public. Second, the public funds health systems through taxes, insurance premiums, and out-of-pocket payments — policymakers are spending the public's money.

“The inclusion of multiple stakeholders, including the public [is] the single most important element to fair priority setting.”

In the wake of a growing sense that policymakers are driven by the bottom line and not patient welfare, public engagement can help repair the trust deficit between the public and policymakers (Lengahan and Hunter 1997; Daniels 2000; Ham and McIvers 2000; Ham and Pickard 1998). Moreover, public engagement can enhance the quality of priority setting decisions because members of the public can scrutinize the values upon which these decisions rest.

Public engagement in priority setting allows “non-expert citizens, acting as ‘value consultants’ . . . to combine technical facts with public values into a set of conclusions and recommendations” (Beierle 1999). As Ham (1996) points out, “judgments are likely to be more soundly based and defensible if they have been to public discussion.”

Policymakers have attempted to engage the public in priority setting in only a few settings:

- In Oregon, attempts to involve the public included public hearings, community meetings, and telephone surveys to elicit the public's values (Dixon and Welch 1991).
- In the Netherlands, the public debated services being funded (Lengahan 1999).
- The Swedish Parliamentary Priorities Commission (1995) conducted opinion surveys and citizen's juries.
- In New Zealand, the Core Services Committee used a range of methods to engage the public including questionnaires, public meetings, and discussion forums (Edgar 2000).
- In the United Kingdom, the National Institute for Health and Clinical Excellence (NICE) engages patients extensively through direct consultation and uses a

Citizens' Council to provide recommendations on topics relating to social, ethical, or moral questions (Kelson 2000).

- At a community level, the Winnipeg Regional Health Authority used its Citizens' Council to help identify and refine priority setting criteria (Gibson, Martin, and Singer 2005).

These are important practical examples. However, priority setting occurs at every level of every health system, including governments and regional and district health authorities; pharmaceutical formulary committees; disease management organizations; for-profit and not-for-profit health insurers, hospitals, and clinical programs. There are countless opportunities where the public could be, but have not been, involved.

Publicity

Decision makers in priority setting contexts should publicize the reasons for their decisions so that all stakeholders, including the



Responsiveness on the part of leaders is a key feature in fair decision making.

public, can understand the context-specific value-choices involved. Most decision makers publicize their decisions but are less diligent about publicizing their reasons. The notion of publicity contains but goes beyond the traditional notion of transparency.

“Most decision makers publicize their decisions but are not as diligent about publicizing their reasons.”

Transparency allows others, who make the effort, to look in — like a window. Transparency about decision making processes — who? what? where? when? how? — is crucial to fair priority setting. Transparency can also serve to discourage unethical decision making by providing greater scrutiny on decision makers.

Publicity, however, is active, not passive. It requires leaders to make a deliberate effort to push the message out to stakeholders. Those who do recognize that only a limited number of stakeholders can “sit around the board room table,” and that all stakeholders, including the public, should understand priority-setting decisions.

In a recent example, the Calgary Regional Health Authority developed and publicized explicit criteria (value-based reasons) for their decisions. Consequently, they were able to respond more effectively to challenges from stakeholders to the improved satisfaction of all (Gibson, Martin, and Singer 2005; Mitton and Donaldson 2003). Other examples include the Ontario Health Technology Assessment Committee and the Canadian Expert Drug Advisory Committee. These committees disseminate their funding recommendations by posting their full reports, with reasons, on their websites.

Review

Decision makers should provide a mechanism through which stakeholders can engage with the decision making process and provide new information and arguments to the deliberation about priority setting reasons. A revision or appeals mechanism can help provide a second look at decisions and reasons, and is a rich potential source of otherwise overlooked or underappreciated information and arguments. It is an important quality control measure, and it provides a mechanism for dispute resolution that can help reduce the burden on leaders who often spend an inordinate amount of time dealing with discontent. Ultimately, it displays responsiveness on the part of leaders, which is a key feature of a fair decision-making process.

The University Health Network, a major academic health science center in Toronto, developed an appeals mechanism for its large-scale clinical activity target setting process that helped improve stakeholder

Capturing and Sharing Lessons: A Database of Learning

Any strategy to improve priority setting must be grounded in these two notions: (1) that priority setting occurs at all levels and in all contexts of a health system; and (2) that improving priority setting involves improving public engagement, publicity, and responsiveness. These two notions can be conceptualized as axes in a table and used to provide structure to a database for improving priority setting. Priority setting in Canada (and elsewhere) has been described as a series of unconnected experiments with no mechanism for capturing and sharing the lessons from each experiment (Martin and Singer 2003a). Moreover, though priority setting at each level of the health system influences priority setting at other levels, decision makers seldom discuss these relationships across contexts and have no explicit mechanism for developing a comprehensive, consistent, and coherent priority-setting approach systemwide.

Table 1. Capturing and Sharing Lessons in Priority Setting: a Database of Learning

Contexts	Content Areas		
	Public Engagement	Publicity	Review Mechanism
Health system			
MoH			
PBM & NTs			
Disease Mgmt Orgs			
RHA/DHA			
Hospitals			
Clinical Programs			

engagement and the quality of their priority setting (Madden, Martin, Downey, and Singer 2005). The Ontario Health Technology Assessment Committee (www.health.gov.on.ca) also provides an appeal mechanism regarding its funding recommendations.

A strategy to improve priority setting must be built on a research platform guided by an explicit conceptual framework (e.g., Table 1). The detailed methods of this approach have been described elsewhere as describe-evaluate-improve (Martin and Singer 2003b). In this approach, scholars and

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policymakers can work in collaboration to fill in the cells of the Table 1 matrix with lessons from each specific priority setting context. The key innovation is that this approach provides a systematic evidence base for improving priority setting in each context of the health system.

This approach has three significant advantages. First, it operationalizes the previously vague notion of evidence-based policy making. A database of lessons — good practices and opportunities for improvement — can be interpreted and implemented in each specific decision making context so that, over time, iterative improvements can be evaluated against an explicit framework.

Second, it opens the “black box” of priority setting in a health system and reveals how decisions are made in each context of the system, thus making previously private decisions public. This openness contributes to an ongoing process of social policy learning for both policymakers and the public.

“Health system leaders can create an environment in which difficult limit-setting decisions can be accepted by the public.”

Third, by developing a systemwide practice of policymaking based on explicit context-specific evidence grounded in the key democratic goal of fairness, health system leaders can create an environment in which difficult limit-setting decisions can be accepted by the public — that is, an environment in which no is an acceptable answer. Ultimately, this acceptance is the key to health system sustainability.

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Importance of Community Input

A Moral Framework for Disaster Planning

by John R. Stone

Images of recent disasters irregularly cycle back into consciousness. People, especially minorities and the poor, suffer and die after hurricane Katrina. Our folks wander around tsunami-destroyed cityscapes. Twin towers collapse. These past events, new influenza strains, and looming bioterrorism are motivating major efforts to improve disaster responsiveness and mitigate potential tragedies.

Writers address the ethics that should guide disaster planning. They note the moral importance of community input and remind us that we should avoid further marginalizing our most disadvantaged communities. We should, that is, pay significant attention to how these communities can be involved in disaster planning. This essay is a step in that direction.¹

I used the following strategy to gather my thoughts: I read through the literature and asked myself what ethical principles I would choose to guide disaster planning if I were a member of a minority or poor community. My discussion of the following principles draws on this thought process. Keep in mind that it is a brief overview. Ethical frameworks also need more than principles; but we must start somewhere.

Principle of Equal and Substantial Respect

The respect principle is foundational. Its key element, everyone's equal moral worth, permeates other principles. Respect demands that we "recognize" people as particular individuals rather than as equivalent but faceless bodies.² Recognition here

includes action to ensure people's agency or self-efficacy and relevant capacities.³ I include "equal" and "substantial" in the principle's name, and recommend using the full name, to reaffirm that we are to treat people equally and well.⁴

Principle of Justice

Justice builds on equal and substantial respect.⁵ Justice as fairness requires treating people equally unless there are morally justifiable reasons for doing otherwise. Thus, advantage merely because of race or ethnicity is wrong because it denies everyone's equal moral worth. Justice demands avoiding disrespect and sometimes compensating for prior disrespect, for example, housing discrimination.

In resource allocations, justice includes fairness in who should decide, what influence they should have, and what decision-making processes should be used. It is an issue of practical justice to determine measures that will assure just outcomes and processes. And justice is the reason that communities in the path of disasters should have fair opportunity to influence decisions that affect their welfare.⁶ What "fair opportunity" means is a complex issue beyond this paper. But people should have a strong voice — and stronger, the more they are affected.

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We should pay significant attention to how these communities can be involved in decisions that affect their welfare.

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Principle of Maximizing Utility

Allocations and efforts should aim to produce the maximum community or population benefit (i.e., utility) that the other principles allow.⁷ Everyone's equivalent outcomes should count equally. The community should have a major voice in ascertaining benefits and harms. The principles of justice and equal and substantial respect generally prohibit utility maximization that would sacrifice the worst off to benefit the many.

"Principles of justice and equal and substantial respect prohibit utility maximization that would sacrifice the worst off to benefit the many."

The principle of beneficence is a check against this abuse. Justice and respect provide reasons to give priority to benefiting the worst off. How much priority is beyond the present scope. However, it can sometimes be ethically acceptable to give priority to treating the better off, for example, to maintain a society.⁸

Principle of Beneficence

This well-known principle calls for maximizing benefit and preventing, avoiding, or eliminating harms.⁹ The focus on benefit overlaps with the utility principle, but constraints on harm are checks against sacrificing some for the benefit of others.

Principle of Community

Health, agency, values, and knowledge of communities should be central elements in disaster planning and responses. Community members should play key roles in articulating these elements and in deciding what to do about them. Regard for equal and substantial respect and justice as fair equality of opportunity should guide community involvement.

The community principle denies that focusing on individuals is sufficient. Community knowledge is important in determining how to address both kinds of health, including the structures and personnel vital for community integrity.

Community perspectives are also vital in planning that involves risk assessment.¹⁰ Active community involvement is also a check against violations of justice and equal and substantial respect that a focus on individuals may ignore.¹¹ Fair inclusion of communities will often require cross-cultural education and training.¹²

Principle of Care

To retain their humanity and compassion, decision makers should remain emotionally attuned to people's potential or actual loss of life and suffering. To implement the care principle, for example, decision makers might periodically look at Katrina and post-tsunami images.

Principle of Trustworthiness

Rather than a primary emphasis on trust, ascertaining, developing, and sustaining trustworthiness should be the basic focus of disaster planning. Minority and poor communities cannot assume that disaster planning and existing structures can be trusted to address their needs fairly and respectfully.¹³

Deliberative Decision Making

In applying these principles, many writers rightly stress the importance of fair decision processes in a deliberative approach. Such processes are important because these principles may give conflicting guidance and their exact applications are undetermined. Transparency about reasons and positions, to promote public accountability, is one recommended assurance.¹⁴ Guidelines for fair process are a protection against abuses of power that can undercut the interests and mute the voices of minority and poor communities. But assuring such fair process generally will

require significant assurances and recourse under the law. Much more work is needed here.

On Rights, Justifications, and Objections

Some readers may argue that this account of principles should rest on basic human rights — that rights justify the principles. Others may assert that the principles justify a set of rights that have greater practical impact — that the practical focus should be on "derivative" rights. Both assertions may be correct.

Others might call for extensive general justification. They may state that the hypothetical perspective needs defense, as do the principles themselves. Vagueness and incompleteness are other possible charges. Still others may raise concerns about presumed communitarian elements. These points should be addressed, but at another time.

Conclusion

A moral framework for disaster planning and response is needed that will help insure the



involvement of poor and marginalized communities and outcomes for these disadvantaged communities that meet our highest ethical standards. This paper proposes that the moral principles discussed here should be part of such a framework. These principles are familiar in name, but a community focus suggests other ways to think about their content. Much more work is needed, including what constitutes fair decision making. Rights issues should be addressed and major attention given to how all these elements should intersect with cross-cultural aspects.

Notes

1. I thank Christy Rentmeester for useful suggestions about these issues, Vanessa N. Gamble for useful background about hurricane Katrina and affected minorities, and Janet Stone for valuable feedback on prior drafts. For numerous points that indirectly inform this essay, I thank Annette Dula, Isaac Mwase, Leonard Ortmann, and Stephen Sodeke.

2. T. E. Hill. 2000. *Respect, Pluralism, and Justice: Kantian Perspectives*. New York: Oxford University Press. L. Ortmann has also stressed the concept of recognition.

3. S. Lawrence-Lightfoot. 2000. *Respect: An Exploration*. Cambridge, MA: Perseus.

4. We can treat all equally and badly. See L. S. Temkin. 2003. "Egalitarianism Defended." *Ethics* 113(4): 764-782.

5. On interpretations of justice, see J. F. Childress, R. R. Faden, R.D. Gaare, et al. "Public Health Ethics: Mapping the Terrain." 2002. *Journal of Law, Medicine, and Ethics* 30(2):170-178; and T. L. Beauchamp and J. F. Childress. 2001. *Principles of Biomedical Ethics*. 5th ed. New York: Oxford University Press.

6. See Childress, Faden, Gaare, et al. "Public Health Ethics"; and, concerning diverse voices in decision making, see J. R. Stone. 2002. "Race and Healthcare Disparities: Overcoming Vulnerability." *Theoretical Medicine and Bioethics* 23:499-518.

7. See "Public Health Ethics"; and J. F. Childress, 2003, "Triage in Response to a Bioterrorist Attack," pp. 77-93, in *In the Wake of Terror: Medicine and Morality in a Time of Crisis*, J.D. Moreno, editor. Cambridge, MA: MIT Press.

8. See note 7.

9. See R. Faden, N. E. Kass, and M. Powers. 1991. "Warrants for Screening Programs: Public

Health, Legal, and Ethical Frameworks," pp. 3-26 in *AIDS, Women, and the Next Generation: Towards a Morally Acceptable Public Policy for HIV Testing of Pregnant Women and Newborns*, R. Faden, G. Geller, and M. Powers, editors. New York: Oxford Univ. Press; and Beauchamp and Childress, *Principles of Biomedical Ethics*.

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11. G. J. Annas. 2003. "Terrorism and Human Rights," pp. 33-49, in *In the Wake of Terror*.

12. See Stone, "Race and Healthcare Disparities."

13. L. M. Crawley. 2000. "African-American Participation in Clinical Trials: Situating Trust and Trustworthiness." *Journal of the National Medical Association* 93(12):14S-16S; and V. N. Gamble. 1997. "Under the Shadow of Tuskegee: African Americans and Health Care." *American Journal of Public Health* 87(11):1773-1778.

14. See, for example, N. Daniels. 2000. "Accountability for Reasonableness." *British Medical Journal* 321:1300-1301.

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Regard for equal and substantial respect and justice as fair equality of opportunity should guide community involvement.

Factoring Inequalities into

by Isaac M. T. Mwase

We are told that an influenza pandemic is on its way. The big one! Bigger than the one that claimed more than twenty million people worldwide in 1918-1919. Is that



Isaac M. T. Mwase

enough to scare you? Reject fear, plan! We are told it is not whether but when such a big one will happen. Agencies that look out for our health are so convinced that an influenza pandemic is on the way, each state has filed a plan about how to handle such a calamity.

Professional organizations concerned about our health have been discussing how to handle an influenza pandemic or a similar event. I attended three sessions at the American Society for Bioethics and Humanities meeting in Denver, October 2006. I could only make it to two of many sessions devoted to pandemic and similar disaster preparations at the annual meeting of the American Public Health Association in Boston, November 2006. One session was called "Planning for Pandemic Influenza: Local, State, Tribal and Federal Perspectives"; the other was a poster session on "Disaster Preparedness."

Bioethicists have been writing about what to do in the event of a pandemic. It is crucial that we clarify what we value, the principles we will invoke, and the

processes we will set in motion when a flu pandemic or similar disaster visits us. They reflect on issues ranging from who should receive things in short supply like vaccines, ventilators, and hospital beds, to what each citizen must do to weather the pandemic when there is a near-total paralysis of all the systems that support human flourishing.

It is not surprising that discussions about distribution of things in short supply like vaccines and respirators focus on various prioritization schemes. The fair allocation of scarce resources is a hard problem. The needs of first responders will have to be met to ensure the maintenance of essential services. Health planners are working to ensure that critical social systems will continue to work even if there are extended restrictions of movement to everyone except essential personnel. This is not the place to determine who should get what in the event of a pandemic, but we cannot avoid the task of deciding the equitable and efficient distribution of vaccines and whatever else will be in short supply.

Ten substantive values have been offered to guide ethical decision-making in the event of an influenza pandemic and five to guide the processes for distributing resources in short supply.

Substantive values include individual liberty, protection of the public from harm, proportionality (restrictions to liberty should not exceed what the pandemic

context necessitates), privacy, duty of healthcare professionals to provide care, reciprocity, equity, trust, solidarity, and good stewardship. And if decision-making processes are to command the confidence of the public, especially minority groups, the procedures must be reasonable, open and transparent, inclusive, responsive, and accountable.

"Ten substantive values have been offered to guide ethical decision-making for a pandemic influenza pandemic and five to guide the processes for distributing resources in short supply."

We all need to prepare to have some of our freedoms restricted. We may not be able to go to ball games, malls, churches, or temples and other places where we gather in groups. Travel may be restricted. Movement to and from certain areas may be restricted. Public health officials in every state will be directed by the Department of Homeland Security on the best measures to ensure the safety of the public from the effects of the influenza virus.

The Centers for Disease Control and Prevention (CDC) is helping citizens prepare for an influenza pandemic. The CDC preparation website offers a family guide, checklist, and information sheets. It also describes what may likely happen when a pandemic occurs:

Pandemic Flu Planning

- Social disruption may be widespread.
- Being able to work may be difficult or impossible.
- Schools may be closed for an extended period of time.
- Transportation services may be disrupted.
- People will need advice and help at work and home.

The public therefore must prepare accordingly. Specifically families should ensure that they have an adequate supply of water and food. Choose foods that are

- nonperishable and don't require refrigeration,
- are easy to prepare in case you are unable to cook, and
- require little or no water, so you can conserve water for drinking

In the aftermath of Katrina, however, we have to think ahead about how to help the poor, those with poor or no health literacy, and those poorly connected to social systems. During Katrina, hundreds of poor people found themselves trapped by the waters for lack of transportation. Whether and how they could have been transported to safety is a question that haunts us even now. The measure of a great society is how it takes care of its most vulnerable members. We failed during Katrina. We must not fail in the event of pandemic flu.

In the event of a pandemic, the most vulnerable will unlikely have the supplies recommended by the CDC. Preparations for pandemic flu should provide an incentive for addressing some of the key critical social determinants of poverty and poor health. We should also mobilize institutions whose mission it is to take care of the poor. Charitable agencies and faith communities have to prepare to be called upon to distribute essentials to vulnerable populations.

The CDC preparation website offers a family guide, checklist, and information sheets.

The prospect of pandemic flu need not alarm or paralyze us with fear. We can address our fears in part by having plans that work for every level of our interconnected lives. Planning is taking place at the federal, state and local levels. Agencies and health departments are getting ready. Citizens have to prepare for pandemic flu by having enough supplies and keeping themselves informed. All of us who are aware should develop plans to take care of the most vulnerable members of society.

For further reading

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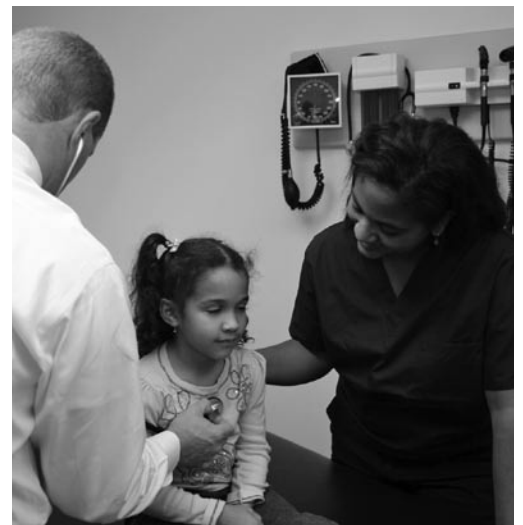
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Bioethics and Disparities

A Conversation with John Stone

John R. Stone, MD, PhD, is an Adjunct Professor in the Center Health Policy and Ethics at Creighton University in Omaha, Nebraska. He works on bioethical issues related to minority health, race, ethnicity, diversity, and community. Social justice and issues of respect are two of his primary concerns.



John R. Stone, MD

Dr. Stone joined the Center for Health Policy and Ethics at Creighton University in 2006, after seven years with the Tuskegee University National Center for Bioethics in Research

and Health Care, Tuskegee, Alabama. Prior to graduate school and his work at Tuskegee, John practiced cardiology for many years in Missoula, Montana, where he co-founded an Institute of Medicine and Humanities.

Practical Bioethics visited with Dr. Stone about bioethics and reducing healthcare disparities.

1. What for you is the relation between medicine and ethics? (How did you go from cardiology to philosophy to policy work related to the health and healthcare of racial, ethnic, and socioeconomic minorities?)

My colleagues trained in top programs and practiced medicine accordingly. But standard medical training and concepts were clearly and radically inadequate. Healing persons (versus diseases) was marginalized [so] we founded the Institute for

Medicine and Humanities. Enlightened leadership at St. Patrick Hospital and the University of Montana made it possible.

I took philosophy courses. The field called to me. I long had a concern for disadvantaged people. My dissertation involved social justice.

Tuskegee embedded me in racial and ethnic issues regarding health and healthcare inequalities. Whiteness, including dominance, privilege, and supremacy, became a focus. On white supremacy, Charles Mills' work is very enlightening. Feminist analyses are important. Iris Marion Young's work has been a great resource on diversity and deliberative decision-making.

2. How in your opinion does bioethics help – or hinder – efforts to respond to health and healthcare disparities?

Bioethics hinders such efforts through its relative silence. With important exceptions, it targets provider-patient issues and ignores structural problems and inequities. But scrutiny of unjust and inadequate policy is increasing.

For bioethics to help, understanding and transforming whiteness is crucial. Catherine Myser's work is an important beginning. Bioethicists should examine multiculturalism at structural and practice levels. They should promote needed changes in policies and educational programs, promote outcome studies, and move into the center of work about disparities. And, as Paul Farmer argues, bioethics should add strategizing and change-agency to its focus on analysis.

3. How does your being white and better advantaged than some members of the groups among whom you work affect you and the less advantaged members of those groups?

Remaining mindful of my multicultural origins and accidental advantages is helpful. I seek to absorb — in mind and heart — the violence, lynching, mayhem, medical experiments, exclusion, and discrimination that whites have wreaked on African Americans and other minorities. Vehicles include discussions with colleagues of diverse backgrounds and studying histories and analyses. Reviewing data and analyses about whiteness is also useful, as well as information about various peoples and the continued inequities imposed on them.

All that helps me accept that African Americans and others may assume that I am an untrustworthy white, clueless and silent about their heritage, their lives, his unearned advantages, and his whiteness.

My goals are to show that I am not what they may reasonably presume, make worthy contributions, and apologize when I err. Other aims include openness, flexibility, and mindfulness of my limited perspective. Listening — and more listening — is crucial. Speaking out about racial and ethnic injustice is important. Striving for a deeply respectful and honoring approach to all is crucial. ■

Who Gets the Ventilator?

Case Study and Discussion Questions

Until recently, the youngest children had huddled together on a lumpy couch in the den every Friday night to share popcorn and apples while viewing a video they had rented from their public library. But because of widespread influenza, the library is temporarily closed, and the children's only entertainment is books they have already read. They pretended to read, but they could hear their sister Laura going back and forth from the kitchen to their Dad's bedroom. Mr. Kelly had been ill for several days, possibly a cold, more likely, the new flu virus. "He's getting worse," they heard Laura tell their mom. Then, after an ominous silence, Ms. Kelly told her daughter to call 911.

The ambulance was not available so the dispatcher told Ms. Kelly to get the neighbors to help transport Mr. Kelly to the hospital. The admitting room was full, but a kind of order prevailed. The long hall between the emergency bay and the surgery was lined with beds. Young people, children, old people from several neighborhoods rattled and coughed; no one looked at another, each one begged silently for help. Very few nurses were visible in the long hall.

A young doctor whom Ms. Kelly had never met soon examined her forty-five-year-old husband. "He's strong, but his fever is very high," she said. "He is also experiencing respiratory failure and needs a ventilator." She patted Ms. Kelly's arm. "We will give your husband the best care we can under the circumstances," she said, "but we don't have enough ventilators to go around."

"Please, Doctor. It's not just us," Ms. Kelly pleaded. "Everyone depends on Joe."

The doctor smiled wanly. "I'm sorry," she said, "but we have to do what's best for all our patients." Ms. Kelly nodded. She had served on a regional committee for pandemic planning.

Questions for Discussion

Reflect on and discuss the following questions with your ethics committee or other colleagues.

1. What would you do if you had two or three patients who needed a ventilator and only one ventilator? What is your duty in such a case, and to whom?
2. When should these decisions be made, and by whom? How would you present this view in a formal planning process?
3. List some of the values that you think decision makers should consider in deciding who gets treatment. Share this list with other members of your ethics committee or community discussion group. Talk about competing values.
4. What are the goals of triage in most medical emergencies? How might these goals be different in times of a pandemic illness or other large-scale disaster?
5. Create a brief list of priorities for deciding who should be treated when not all people can be treated.
6. What factors (e.g., intensity or severity of disease, prognosis if treated or not treated, cost of treatment, the patient's age, quality of life, social value, gender, or ethnicity), affect how you will achieve your goals?

Case Studies are a regular feature of Practical Bioethics. For more cases, visit www.practicalbioethics.org or ask about our online discussion group. Email your comments on this case or your request to join the discussion group to bioethic@practicalbioethics.org.



What would you do if you had two or three patients who needed a ventilator and only one ventilator?

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Deciding What Is Fair

(Continued from page 2)

No doubt, as most of these essays reveal, issues of rationing hit home hard when preparing for an imminent pandemic or other major disaster. Such events force us to consider rationing on levels that are macro, institutional, professional, social, and personal.

On a macro level, how can we cultivate public trust in federal, state, and local efforts to balance government powers, the good of community, and individual rights and liberties?

Professionally, what is the scope of healthcare workers' duties to patients? How do we resolve conflicts between duties to patients and duties to family? And what about the institution's duty to safeguard and support staff who face disproportionate risks during disasters? Issues of public safety and support compel us to balance the good of community and individual liberties. But what ethical principles justify restrictions on individual liberties?

How do we fairly ration scarce medical treatment such as vaccines, retroviral agents, and disposable ventilators? Who is treated after frontline workers and first responders? Those with high risk conditions or those who are healthier with normal life spans yet to live?

Briefly considered, the first of these alternatives is the position of the U.S. Department of Health and Human Services as expressed through the National Vaccine Advisory Committee and the Advisory Committee on Immunization Practices. Here, the rationale is clearly to minimize illness and death and protect the most vulnerable.

The second alternative was suggested by E. Emanuel and A. Wertheimer (NIH, Clinical Bioethics, in Science May 2006). Their rationale: sustaining a "life-cycle" principle enables most people to live through a normal life span and better ensures future social stability.

This choice — between (a) minimizing illness and death, and (b) maximizing life-cycle opportunities — embodies the anguishing complexities embedded in the elemental tension between self and other. How we configure the discussion reflects values that will necessarily compete and

clash. How do we — can we — arrive at a consensus in view of this clash? Ethical issues undergirding pandemic preparedness necessarily reflect the wider issues pertaining to resource allocation and justice in healthcare.

Underscoring our concern for this issue, the Center for Practical Bioethics and the Kansas City Regional Hospital Ethics Committee Consortium have recently partnered with the Emergency Planning division of the Mid-America Regional Council (MARC) to more closely examine ethical issues in the context of disaster planning and mass-casualty events. The new team, the Ethics in Disaster Planning Taskforce, comprises hospital ethics committee representatives, MARC hospital representatives, and Center and MARC staff.

The purpose — to arrive at morally sound guidelines and policies to assist healthcare institutions in disaster situations — is daunting and the work is challenging. Nonetheless, ethically sound standardized procedures are urgently needed. Our first charge as a task force will be to establish protocol for the fair allocation of ventilators, certainly a scarce resource even in the absence of a major crisis. Only through such collaborative efforts can evenhanded rationing begin to make sense.

Our discussion in this issue of *Practical Bioethics* serves, then, as prelude to an ongoing dialogue here at the Center for Practical Bioethics, with and among ethics committees, the communities they serve, and other critical stakeholders.

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