Chapter 19
Communitarian Bioethics

Communitarianism is often viewed as the polar opposite of liberalism, as seeking to preempt individual choices by relying on communal normative criteria and authorities. Common good considerations are said to replace respect for autonomy. Accordingly, for example, people with infectious diseases are to be incarcerated, the way Cuba deals with those who contract HIV (Hansen and Groce 2003, p. 2875). Indeed, such authoritarian communitarianism has been championed by the leaders and some public intellectuals of East Asian nations, especially Singapore and Malaysia (Jiang 1998; Bell 1995). One major reason many, especially in the West, reject this kind of communitarianism is that they hold autonomy in high regard.

The same challenge does not apply to responsive (or liberal) communitarianism.[1] This communitarianism seeks to balance autonomy with concern for the common good, without a priori privileging either of these two core values. And it seeks to rely on society (informal social controls, persuasion, and education) to the greatest extent possible and to minimize the role of the state (law enforcement) in promoting compliance with the norms that flow from these values. Responsive communitarianism is often confused with, or treated as part and parcel of, authoritarian communitarianism, though the two differ as much as social democratic socialism differs from Soviet socialism.

Although responsive communitarianism's starting point is the recognition that the tense relationship between autonomy and the common good must be worked out rather than starting with the assumption that one of these core values trumps the other, it expects treatment to differ from one society to another and among different

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[1] The responsive communitarian position was first articulated by a group of scholars and activists in the early 1990s, including William A. Galston, Mary Ann Glendon, Philip Selznik, Jean Bethke Elshtain, and Amitai Etzioni. They issued a platform (Communitarian Network 2010) that found many endorsers across much of the political spectrum.

A. Etzioni, *Happiness is the Wrong Metric*, Library of Public Policy and Public Administration 11, https://doi.org/10.1007/978-3-319-69623-2_19

historical periods. Thus, in totalitarian societies and theocracies, such as those in Singapore and Iran, those who advocate the balance that responsive communitarianism favors would need to promote autonomy, while in societies in which individualism is rampant, such as the United States was in the 1980s, the advocates of responsive communitarianism would need to promote more attention to the common good. That is, societies often need to move in opposite directions from one another to achieve the same end balance.

19.1 Earlier Treatments of Communitarian Bioethics

Medicine is typically non-communitarian in the sense that it usually does not concern itself with the common good. The individual patient's good is at the center of nearly every discussion. Indeed, earlier communitarian examinations of bioethics focused on the observation that American bioethicists tend to err on the side of considering the patient as an individualistic being and view autonomy as the supreme value, according to which the patient's right to personal choice is paramount. Daniel Callahan quotes Joseph Fletcher, stating that bioethics is based on "the idea of personal choice as the highest moral value and the struggle against nature as medicine's most liberating mission" (Bell 1995). Ezekiel Emanuel, in his essay on the care of incompetent patients, points out that the understanding of the "best interests" of a patient in this individualist vision of health care is based upon the degree of pain a procedure would inflict on that person (Callahan 1994). Jeffrey Blustein explains this conception of autonomy in health care, stating, "It rests … on a picture of the person as a separate being, with a distinctive personal point of view and an interest in being able securely to pursue his or her own conception of the good" (Blustein 1993).

Communitarianism in these writings is often viewed as leaning in the authoritarian direction, at least in the sense that it is centered on the common good and not autonomy. For instance, Lawrence O. Gostin (2002) defines communitarianism as a tradition that "views individuals as part of social and political networks, with each individual reliant on others for health and security. Individuals, according to this tradition, gain value from being a part of a well-regulated society that seeks to prevent common risks". Similarly, Veena Das (1999) looks to a communitarian conception of bioethics to allow bioethicists to "find alternative anchoring concepts to those of patient autonomy." Ogunbanjo and van Bogaert (2005) define communitarianism as "a model of political organization that stresses ties of affection, kinship, and a sense of common purpose and tradition."

To illustrate briefly the generalizations introduced so far: a liberal bioethics may stress that patients should be free to instruct their physicians not to disclose their conditions to others (although exceptions may be recognized, such as when dealing with minors, infectious diseases, or attempts to commit homicide). The patient should also be free to argue for an order not to be resuscitated or refuse other treatments, disregarding the values and feelings of the patient's family and surely of his community. Communitarianism is then depicted as the opposite position, in which

the family can instruct the physician not to disclose to the patient that his condition is terminal, can demand continued health care services, and so on. However, in the terms here employed, this second position is a form of authoritarian communitarianism, because it is centered on the values of the community and disregards the value of autonomy. Responsive communitarianism favors seeking to work out the conflict between the patient and the family and developing mechanisms for its resolution.

Some of the early writings by bioethicists about communitarianism do reveal recognition of the two, sometimes conflicting, core values—autonomy and the common good—although they do not employ these two terms. Thus, Callahan (1994) defines communitarian bioethics as seeking to "blend cultural judgment and personal judgment." Thomas H. Murray (1994, pp. 32–33) writes that many theorists believe "the solution is not to abandon autonomy…. But autonomy can only be a part of the story about how we are to live together, how we are to make families and communities that support the growth of love, enduring loyalties, and compassion."

Mark Kuczewski (2001, p. 136) recognizes explicitly that one is dealing here with two rather different kinds of communitarianism. He compares "whole tradition communitarians" with "liberal communitarians": the former requires an acceptance of the full cloth of a single tradition and does not allow for compromise or even significant communication across the borders of communities, while the latter stresses respectful "moral deliberation" as a way to communicate and coordinate moral expectations across traditional boundaries.

Before proceeding, I must explicate the term 'the common good.' It refers to those goods that serve the shared assets of a given community: for example, preserving national monuments, supporting "basic" scientific research, advancing national security, protecting the environment, and promoting public health. Contributions to the common good often offer no immediate benefits to any one individual, and it is often impossible to predict who will gain from them or to what extent, in the longer run. Often, investment in the common good is carried out because it is considered the right thing to do, by itself and for itself, not because we or our offspring will personally benefit from it.[2]

19.2 Society (Community) vs. State

Responsive communitarianism holds that the more one can rely on norms rather than laws and on public education, moral persuasion, and informal social controls rather than on law enforcement, the better the society. (I use 'better' to mean ethically preferred, in a non-consequentialist sense, rather than solely on the basis of cost-benefit analysis, although such an analysis can have ethical implications that should be taken into account). The main reason is that societal processes can change preferences and lead to truly voluntary compliance, while coercion leaves opposing

[2] For additional discussion, see Alex John London (2003), Kuczewski (2009), and Etzioni (2004).

preferences intact. It, hence, invites attempts to circumvent the law and tends to generate a sense of alienation (Etzioni 1975).

A telling example is the way Prohibition was introduced versus the way public smoking was banned. The enactment of Prohibition was not preceded by the building of a normative consensus and instead relied heavily on law enforcement. It failed to suppress the use of alcohol and greatly increased the corruption of the American legal and political system. Moreover, it is the only constitutional amendment that was ever repealed. In contrast, although it took some 25 years to build wide societal support to ban smoking in public spaces, once these laws were introduced, they served to lock in an already very well established norm, which is almost completely self-enforcing.

Similarly, responsive communitarianism would urge, for example, that long before one considers mandatory HIV testing, let alone forcefully isolating people who have contracted HIV, one is obligated to engage in public educational campaigns that encourage such testing and to work with the communities of those most at risk to encourage their members to be tested. And rather than open a market in human organs to incentivize more people to donate organs, which are in short supply (Erin and Harris 2003, pp. 137–138) one should appeal to people to make the gift of life. A colleague has suggested that the debate about how best to increase the supply of organs may be an instance of the debate between those who see the world through the eyes of rational choice and seek to reduce all conduct to self-interest, and those who hold—as I do—that people are indeed influenced by incentives and disincentives, but also by moral considerations, which change their preferences. It is not possible to deal with this debate here, and I have treated it extensively elsewhere (Etzioni 1988).

At the same time, responsive communitarianism does recognize that there are conditions under which the state must be involved, although it is best used as the last, rather than the first, resort. For instance, when people infected with a highly communicable disease that has fatal consequences do not heed calls to remain at home until they cease to be infectious, the state has an obligation to enforce their quarantine. Historically, this issue has arisen with regard to the treatment of people with leprosy, tuberculosis, and, more recently, severe adult respiratory syndrome (SARS) and H1N1 influenza.

Gostin (2002) provides a powerful case for a communitarian approach to similar issues, such as a bioterrorist attack or a severe medical emergency. He points out that excessive concern for autonomy and neglect of the common good have led to a focus on individualized achievements in health care at the cost of severely underfunding the public health infrastructure and ignoring the needed adaptations of public health laws. As a result, public health agencies do not have the capacity to "conduct essential public health services at a level of performance that matches the constantly evolving threats to the health of the public." At the same time, public health law has fallen off the radar and is now "highly antiquated, after many decades of neglect." Finally, the debate about the role of the government in providing health care, reignited in the United States by the Obama administration, has some strong

communitarian dimensions, as does the reliance by insurers on community ratings versus "cherry picking" the healthy and the wealthy.

19.2.1 Which Community?

The term 'community' is often associated with small, traditional, residential communities, such as villages. However, in the modern era, communities are often non-residential and based on ethnicity, race, religious background, or a shared sexual orientation. Moreover, people are often members of more than one community. Finally, it is often productive to consider communities as nesting within more encompassing communities, such as local ones within a national one. People are hence subject not merely to tension between their personal preferences and the values and norms promoted by their community but are also subject to conflicting normative indications from various communities.

The family can be viewed as a small community. In bioethics, strong champions of autonomy, as well as some feminists, suggest that each adult member of the family should make her or his own choices and that other members of the family should have no status in these decisions (Blustein 1993). In contrast, discussions about severely ill neonates whose parents seek to allow the infant to die because it will benefit other siblings tend to attach considerable weight to the welfare of the family as a whole.

John Hardwig (1990) moves us toward a responsive communitarian position when he writes that "the interests of patients and family members are morally to be weighed equally" and "to be part of a family is to be morally required to make decisions on the basis of thinking about what is best for all concerned, not simply what is best for yourself." Hardwig adds, "That the patient's interests may often outweigh the conflicting interests of others in treatment decisions is no justification for failing to recognize that an attempt to balance or harmonize different, conflicting interests is often morally required." He leans somewhat in the authoritarian direction when at one point he claims that "considerations of fairness and, paradoxically, of autonomy therefore indicate that the *family* should make the treatment decision, with all competent family members whose lives will be affected participating." Thus, a less authoritarian position would suggest that, for instance, if nine out of ten family members agree that treatment should be stopped for a given member, but the member—who is competent—rejects this conclusion, the family's wishes should not carry. However, the person does owe the family members a careful consideration of their values, reasons, and needs.

Jeffrey Blustein (1993) also articulates a responsive communitarian position. He holds that while final decision-making authority ought to remain with the patient, medical personnel and society ought to focus on integrating family members into the decision-making process to support the patient's ability to determine the best option—taking into consideration the interests of those most important to him or her.

When bioethical communitarian considerations turn to more encompassing communities, especially to transnational ones, a whole host of additional issues arise. They often center on the question of which community's values should prevail. These issues have been debated with regard to numerous topics, ranging from female circumcision to the testing of new drugs overseas. Whether one can apply here the dual approach of combining respect for the cultural autonomy of various cultures and the concern for a global common good is a topic that must be left for another discussion. The same holds for the numerous inter-community issues that arise when a national culture, values, and laws conflict with the culture, values, and habits of various immigrant groups or confessional groups that are members of the same national society.

Ezekiel Emanuel (1987) points out that the various criteria for what is in the best interest of the patient are affected by what a given community considers "the good life." He writes, "This solution derives from communitarianism, a philosophy that incorporates the truths of utilitarianism and liberalism, but transcends both by arguing that ethical problems can be resolved only by accepting a public conception of the good life while rejecting the conception of the good particular to utilitarianism." Emanuel favors allowing each community to determine its own concept of the "good life" on the grounds that (a) it is impossible to answer this question on neutral grounds and (b) we are a pluralistic society, and hence, should respect the values of various member groups such as Orthodox Jews and the gay community. This position is very much in line with a communitarian position, but it raises the question of whether there is room for nationwide or even transnational communal criteria and policies.

As I see it, the answer lies in a position referred to as "diversity within unity." Accordingly, on some issues, it is clear that the most extensive community—often the nation, but increasingly also transnational communities such as the EU—should and do provide the normative criteria. On other matters, diversity of the kind Emanuel depicts is fully appropriate. And, in still a few other instances, one should expect that there will be room for disagreement about what "belongs" to the community at large and what to smaller, member ones. Examples of those that are best guided by the most encompassing communities are issues that concern basic rights (e.g. few would leave it to local communities to rule on whether gay patients or members of a given racial minority should be denied service) and the moral claims that urge people to donate organs, blood, and time. In contrast, allowing different groups to rely on faith healers up to a point is an example of local community values influencing biomedical decisions.

In the United States, an example of communities defining ethical care concerns the conditions under which parents can deny medical care for their children. Some states mandate treatment when it is a question of life and death, regardless of the parent's request to forego care, while others allow extreme latitude in the decision making options of parents, including choices made about lifesaving interventions. In contrast to this state-by-state determination of critical care decisions, there is a nationwide consensus that in matters less than life or death, parents should be allowed to refuse treatment for their children in order to maintain their personal perception of "the good life."

In short, diversity within unity[3] provides a responsive communitarian model of granting some discretion to member communities while also maintaining select values of the most encompassing conceptions of the common good. The fact that, in some matters, it is unclear which community should prevail does not obviate the merit of this design, which stands out when one compares the diversity within unity position to those that favor the national state and those that favor turning these matters into the domain of each member community.

19.2.2 Procedures and Criteria

Communitarians must concern themselves with procedures and criteria that allow one to work out personal decisions and public policies in the face of conflicting values. A major way to proceed is through moral dialogues. Examinations of actual processes of consensus building, especially when they concern normative matters, show that individual preferences and judgments are largely shaped through interactive communications about values—that is, through moral dialogues that combine passion with normative arguments and rely on processes of persuasion, education, and leadership. Moral dialogues focus more on values than on facts. Although passionate and without a clear starting and ending point, they often lead to new shared moral understandings. Such dialogues led to the formation of a new sense of duty to protect the environment, to reject racism and sexism, to oppose the war in Vietnam, and many other such society-wide shared understandings.

The redefinition of death that took place in the United States illustrates the ways in which moral dialogues work. In 1968, an ad hoc committee at the Harvard Medical School published a report that defined an irreversible coma as "brain death"—a new definition of death. The report, put together by academics and medical professionals, did little to redefine the public perception of death. However, in 1972, a young woman named Karen Ann Quinlan fell into a persistent vegetative state. After weeks of life support, her parents asked that she be taken off the machine and be allowed to die. The hospital refused, so the parents sued. Although Quinlan's case did not meet the definition of brain death, her case brought the issue to national attention (Jonsen 1998). There followed extensive and widespread dialogues in various communities spurred by the media, out of which gradually grew a consensus accepting brain death as a morally acceptable definition of end of life and substituted this definition for the previous belief that one ought to do "all one could" to keep one's loved ones alive.

Another way to work out the balance between autonomy and the common good as it applies to specific matters is to leave these issues to courts or to legislatures. Should people be required by law to vaccinate their children? Under what conditions may people be subjects of research? Can one require people who have been arrested—but not yet convicted—to yield their DNA, the way their fingerprints are

[3] For more discussion, see Etzioni (2003).

collected? These and many other bioethical considerations are best first subject to moral dialogues, assisted by bodies such as ethics committees in hospitals or the Presidential Commission for the Study of Bioethical Issues, but—especially given the growing volume of such policy matters—some ought to be worked out by courts and legislatures.

Finally, communitarian bioethics leads one to suggest criteria that moral dialogues, judges, and lawmakers may draw upon. One is the relative adverse impact on the two core conflicting values that flow from the adoption of a given policy. That is, when autonomy must be much curbed for minor gains to the common good, responsive communitarianism suggests autonomy should be given the right of way, while public policy should lean in the opposite direction if the gains to the common good are substantial and the sacrifice of autonomy is minimal (Etzioni 1999).

These criteria would help explain the position articulated by Tom L. Beauchamp (1994, pp. 18–19), who argues that society should switch its conceptions of the public and private good in terms of euthanasia and organ donation. Euthanasia, currently considered an issue where the public determines its application, ought to be a private matter, according to Beauchamp, because that is the logical conclusion of a culture that allows patients extreme latitude to determine their treatment up to (but currently not including) death, with the assumption that personal care choices have more impact on personal autonomy than they do on society at large. At the same time, organ donation, with its widespread implications for the well-being of the community, ought to be moved out of the realm of personal decision making and into the public arena, putting the focus on the public good, which is more impacted by organ donation decisions than is individual autonomy.

Other criteria indicate that one ought to find ways to absorb the side effects. For instance, if one introduces a policy that calls for testing newborn infants for HIV, special care must be taken to keep the results confidential, lest the mother lose her job, housing, or insurance.

19.2.3 Third Values

So far I have limited the discussion to two core values because these are the ones that define the main differences among liberals, authoritarian communitarians, and responsive communitarians. However, bioethical judgments obviously can and do draw on additional values, and the ways in which these can be treated in this context remain to be discussed. Much of this discussion must be deferred because it requires rather extensive deliberations. However, the main issue at hand can be illustrated by pointing to the four values often quoted by bioethicists, drawing on the influential work of Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics* (2008). These are respect for autonomy, nonmaleficence, beneficence, and justice.

Three of the four principles in this quartet focus on the individual. The meaning of autonomy in a bioethical context has already been covered in the first parts of this chapter. Nonmaleficence also focuses on the well-being of the individual patient: do

no intentional harm. Beneficence, the third principle, is defined as an obligation to advance the healthcare interests and welfare of other individuals—because we have ourselves received benefits. Justice, the fourth principle, raises a host of complicated issues that so far have not been addressed extensively by communitarians.

19.2.4 Social Justice: A Case Study

One major place where the study of bioethics and social justice converge is in examining the normative criteria according to which scarce resources are allocated. For instance, when triage takes place, rationing is called for, and the argument is advanced that after a certain age, senior citizens should be granted only ameliorative care.

Here the focus is on questions raised in the United States, as well as in several other countries in the wake of the 2008–2009 great recession, by fears that the economy will continue to grow slowly and suffer from high levels of debt and a high rate of unemployment. Various public efforts were launched to reduce public outlays in general and those set aside for Medicare and Medicaid in particular. Indeed, it was argued that because "entitlements" command about 60% of the federal budget, and given that a good part of the remaining 40% is dedicated to defense and interest that must be paid, unless entitlements—and especially Medicaid and Medicare—were cut, it would be impossible for the United States to "put its fiscal house in order." Both legislators and media mavens argued that cutting into the social safety net was not merely necessary to reduce the deficit, but that it was mathematically inevitable. As Senator Michael Bennet (D-CO) put it, "We can't solve our budget crisis without dealing with our entitlements" (NPR 2010).

The "inevitable" need to cut into social safety nets is inevitable only if one refuses to collect additional revenues, such as through a carbon emissions tax, cap-and-trade system, or value-added tax. To give but one example, a carbon emissions tax of $10 per ton of carbon content could generate $50 billion a year and generate several other desirable outcomes. Whether or not one agrees with such revenue generating moves, they demonstrate that cutting entitlements is a matter of choice, not a mathematical necessity.

The normative case for social safety nets is often made on social justice grounds. These programs have lifted millions of Americans out of poverty, more than all other federal programs combined, and they transfer a modest amount of resources from more affluent Americans to those less endowed. They are also defended on social contract grounds. Senior citizens and those late in their careers have planned their whole lives around the assumption that the safety nets they paid into would be there when they retired or became infirm. To violate this contract is manifestly unfair. There is another moral argument to consider. If we must make cuts, we ought to first cut those budget items that in effect pay for harmful activities and then those without any discernable social benefits, before we even consider touching those that are beneficial—even if the benefits are limited and their costs are high. This is a sociological version of the medieval medical aphorism: first, do no harm.

In 2010, total Medicare spending was estimated to be over $500 billion (Congressional Budget Office 2010). This program was projected to run out of funds before Social Security—perhaps as early as 2029. In December 2010, the National Commission on Fiscal Responsibility and Reform issued a draft report that called for limiting what the nation could spend on Medicare, while others called for delaying the age at which one qualified for care (The National Commission on Fiscal Responsibility and Reform 2010). States moved to cut services in ways that were harmful to Medicaid patients. In Arizona, Governor Jan Brewer asked the Obama Administration for permission to remove 280,000 people from Medicaid rolls. In California, Governor Jerry Brown limited doctor visits and prescriptions for Medicare beneficiaries. In Georgia, Governor Nathan Deal proposed to end Medicaid coverage for adult dental, vision, and podiatry treatments, and South Carolina proposed to end hospice care. These and other such cuts seem morally unjustified as long as there are ways to fund these programs by curbing services that are harmful or have no proven benefit.

The United States spends twice as much on administrative costs for health care than do many other countries. One study found that U.S. administrative costs amount to $30 out of every $100 spent on health care, compared to $17 in Canada (Aaron 2003). There are many reasons the U.S. cannot match Canada's parsimonious ways, but if it could cut only part of the difference in administrative overhead, it would save a good part of what Medicare needs to remain financially solid. Some experts are skeptical when people argue that one can gain the needed funds by eliminating fraud and abuse. Yet one is duty-bound to increase the efforts to plug the leaky bucket before denying seniors the right to dip into it when they are ill. One report demonstrated that the Medicare fraud industry in South Florida by 2010 was larger than the cocaine industry, due to the relative ease of swindling Medicare: there was less risk of exposure and less risk of punishment if caught (60 Minutes 2009). Criminals buy patient lists and bill the government for expensive items ranging from scooters to prostheses, costing the government about $60 billion a year. Because Medicare is required by law to pay all bills within 30 days and has a small accounting staff, it often cannot vet claims before the checks go out. By the time Medicare authorities find out a storefront's bills are phony, the criminals have closed their operation and moved on. From a moral viewpoint, it seems wrong to cut anyone's benefits until the government triples its accounting staff and quadruples the number of such criminals in jail.

As much as $325 billion is spent every year in unnecessary treatments in the health care system. Cutting back on these procedures would reduce the deficit without denying benefits to anyone. An even stronger case can be made for increasing efforts to reduce the estimated 98,000 deaths caused every year by medical error.

All this is not to say that one should rule out adjusting benefits. However, it is morally wrong to deny benefits to those who retired or plan to retire or are ill and infirm before the nation greatly increases the number and prerogatives of those who seek to curb the billions siphoned off by criminals, wasted by bureaucrats, and squandered on useless medical interventions that can make people sicker—or even kill them.

19.2.5 Add the Common Good

Finally, it is important to note that even the nuanced and enriched set of normative principles developed by Beauchamp and Childress does not include a concept of the common good above and beyond the concept of justice. For instance, they do not discuss conditions under which individuals have to accept various sacrifices for the good of all. Thus, the kinds of concerns Gostin and communitarians more generally have about preventing the spread of infectious diseases, responding to bioterrorist attacks, protecting the environment, balancing preventive and acute medical treatments, and determining the extent to which one can foster or force limits on individual choices for the public good do not find a comfortable home in the most widely followed bioethical texts. Hence, concern for the common good, responsive communitarians would argue, should be added to the already existing core values on which bioethics draws.

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