Chapter 8
The Duty to Care: Democratic Equality and Responsibility for End-of-Life Health Care

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8.1 Introduction

All forms of egalitarianism have important implications for health care. In her classic essay, "What is the Point of Equality?" Elizabeth Anderson sketches a version of egalitarianism that she calls "democratic equality" (Anderson 1999). I argue that Anderson's theory of democratic equality, when suitably modified, is more plausible than her luck egalitarian critics have claimed and that it has important implications for health care generally and end-of-life care in particular. Anderson's Democratic equality is able to account for some of the main insights of luck egalitarianism while avoiding its counter-intuitive implications. In addition, democratic equality can explain the role of responsibility in health care while providing a justification of universal health care regardless of prior choices made by those needing health care. In this respect, democratic equality justifies a duty on the part of society to provide care for citizens throughout their lives while setting limits on the scope of the duty. At the same time democratic equality justifies a duty to care for one's own health.

8.2 Democratic Equality

8.2.1 Anderson's Version

Elizabeth Anderson defends an egalitarian view that is based on the equal moral status of persons and directed against hierarchies of moral worth (Anderson 1999,

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p. 312). On the positive side this means that all competent adults are equally moral agents who are capable of exercising moral responsibility and cooperating in accord with principles of justice. Negatively this means that "…distinctions of moral worth based on birth or social identity – on family membership, inherited social status, race, ethnicity, gender, or genes" are to be repudiated (Anderson 1999, p. 312). To respect people is to treat them as moral equals, and this has implications for how we justify our actions. Anderson spells out what this means in terms of a principle of interpersonal justification according to which

> "…democratic equality regards two people as equal when each accepts the obligation to justify their actions by principles acceptable to the other, and in which they take mutual consultation, reciprocation, and recognition for granted" (Anderson 1999, p. 313).

Interpersonal justification requires that people have a voice in how they are treated and access to participation in the creation of policy by which they will be governed. This in turn requires that people have the capabilities that enable such participation. In short, respect for persons as moral equals engaged in interpersonal justification provides compelling reason for society to guarantee those capabilities "…necessary to enable them to avoid or escape entanglement in oppressive social relationships…[and] necessary for functioning as an equal citizen in a democratic state" (Anderson 1999, p. 316). Anderson uses the term "capabilities" in the technical sense spelled out by Amartya Sen and Martha Nussbaum in their capabilities approach (Nussbaum 2000, 2011 and Sen 1984, 1992). Capabilities can be briefly described as opportunities for being in certain states (e.g., being healthy) and doing various things (e.g., participating in government) (Nussbaum 2011, p. 20). Capabilities give one effective access to goods and abilities, though one is at liberty to decide whether to take advantage of the goods and abilities to which one has access. This is important because it preserves liberty and constrains government paternalism. It is particularly important for Anderson who claims, "Democratic equality guarantees all law-abiding citizens effective access to the social conditions of their freedom at all times" (Anderson 1999, p. 289).

The capabilities include meaningful access to goods, resources and services necessary for being a political agent such as voting and petitioning the government as well as capabilities necessary for participation as an equal in civil society (Anderson 1999, p. 317). Moreover, these are also capabilities necessary for the exercise of responsible agency (Anderson 1999, p. 328). In particular, the relevant capabilities necessary for functioning as an equal citizen include "…effective access to the means of sustaining one's biological existence – food, shelter, clothing, medical care…" (Anderson 1999, p. 317). These capabilities are guaranteed over the course of a person's life regardless of the choices made by the person, so long as the choices do not violate the criminal law (Anderson 1999, p. 314). Presumably even criminals lose only those capabilities necessary for a just punishment and not capabilities such as health and adequate diet. It is also worth noting that Anderson's capabilities approach has built in limits, since democratic equality "…guarantees only a set of capabilities necessary to functioning as a free and equal citizen and avoiding oppression" (Anderson 1999, p. 327).

Elizabeth Anderson is working in the tradition of Rawls's theory of justice. In Sections 12 and 13 of *A Theory of Justice* Rawls defends a notion of democratic equality, which he characterizes as combining the difference principle with the principle of fair opportunity (Rawls 1971). I focus on Anderson's version of democratic equality, however, because it enables us to avoid the raft of objections that have been given to Rawls's difference principle and his restriction of democratic equality to free and equal people in democracies. In addition, Anderson's approach is appealing in its relative simplicity compared with Rawls's theory.

8.2.2 Modified Version of Anderson's Version

Anderson's version of democratic equality rests on the notions of moral equality, a principle of interpersonal justification, and the capabilities approach. These need to be clarified, modified or expanded. Anderson holds that competent adults are morally equal and characterizes competence in terms of the ability to exercise moral responsibility and cooperate in accord with principles of justice. If democratic equality is to result in a plausible defense of universal healthcare it must be modified to include future moral agents such as children and those who are temporarily incompetent such as persons in a coma with the possibility of recovery. It should also be noted that people are more or less capable of exercising responsibility and cooperation. As a result, it should not be assumed that all are equally capable of exercising moral agency by taking responsibility and cooperating on the basis of principles of justice. Hence moral equality should be thought of in terms of respecting the equal moral status of those who are or will be capable of exercising moral agency to whatever degree.

The difficulty of determining degrees of responsibility or of setting a minimum level of responsible agency poses a serious problem for any egalitarian theory, including luck egalitarianism, which bases distribution on responsibility (Carter 2011, pp. 543–548). As Ian Carter points out, Anderson and egalitarianism generally need a more detailed account of moral equality than they provide (Carter 2011, pp. 542–543). For our purposes, however, it is enough to note that democratic equality avoids this problem in the case of health care because it does not set the access provided by the relevant capabilities on the basis of how responsible particular individuals are.

Those who struggle to exercise responsibility and to cooperate are well served by accepting a principle of interpersonal justification, but how should such a principle be described? As it stands, Anderson's principle of interpersonal justification is too rigid and open to obvious objections. Reasonable critics such as Shlomi Segall and Lansing Pollack have made it clear that they do not accept her justifications, and Anderson's position seems commit her to dismissing such critics as simply unreasonable (Brown 2005, p. 314; Pollock 2001, p. 255; Segall 2010, pp. 27–47). In certain situations it may in fact simply be impossible to come up with justifications that all others would accept, even taking for granted reciprocation, consultation

and recognition. We would be better off interpreting the principle of interpersonal justification along contractualist lines to require that people make a good faith effort to come up with justifications that are acceptable to others, provided others are reasonable in the sense of being willing to do the same and, when that is not possible, to offer justifications for adopting a decision procedure others could reasonably accept as fair. In some cases such a decision procedure could be majority vote within the constraints of certain civil rights. In other cases it might be having a voice in decisions to be made by an administrative regulatory body or presenting arguments in litigation to a jury of one's peers.

At the level of national policy, I interpret this to mean that legislators and regulators must adopt procedures that allow citizens to have a meaningful voice in legislation and in addition that they must attempt in good faith to justify the laws and regulations that are passed on the basis of background principles – in some cases quite abstract – that are acceptable to reasonable persons subject to the laws and policies even if they do not in fact agree with the way those principles are applied. There may, after all, be intractable disagreement about how to weigh competing values or how to apply them (Daniels 2008, pp. 117–133). For example, policy makers may justify a compulsory vaccination program to protect against human papillomavirus on the basis of health needs and enhanced individual autonomy, even though some may think that the autonomous choice of parents to refuse vaccination for their children should be given more weight. To demand actual agreement on application of principles would make it virtually impossible in a pluralist society to pass laws and regulations.

What Anderson says about capabilities can also be put in terms of rights (Nussbaum 1997). Just as right-holders can decide whether or not to stand on or claim a right, competent adults who are guaranteed capabilities can decide whether or not to take advantage of the access afforded. Moreover, the capabilities guaranteed by democratic equality are just the sort of vital interests that merit the protection of rights – high priority norms that trump competing interests. Anderson speaks in terms of state guaranteed capabilities and does not apply her theory globally. Nonetheless, since all states ought to guarantee these capabilities, on democratic equality, the capabilities are global in scope and the analogous rights can be characterized as human rights. The capabilities will be specified in different ways by different nations depending on available resources and culture, but this is no less true of human rights. Thus, democratic equality provides a defense of human rights that protect civic and political participation in society.

8.3 Implications for Health Care

Democratic equality has obvious implications for health care though they are not spelled out in detail by Anderson. Certainly poor health can become so severe that one is no longer able to function as a free and equal citizen. This is true of both mental and physical health. Severe depression, for instance, makes it difficult to

engage in the highly social enterprise of being a free citizen. Injury, disease and various physical maladies can also reach a level at which it is difficult or impossible to be socially active in one's community. Hence, democratic equality justifies guaranteeing meaningful access to health care or, in other words, a right to meaningful access to health and health care. Individuals are responsible for choosing whether to take advantage of this access or refuse offered treatment. Democratic equality preserves the right of competent persons to refuse medical treatment.

In light of the criticisms of luck egalitarianism offered by Anderson and the criticisms of democratic equality given by luck egalitarians, it is helpful to contrast democratic equality with luck egalitarianism regarding the entitlement to health care. While there are different versions of luck egalitarianism, I will focus on the version given by Shlomi Segall, which he then supplements with other principles of justice. Luck egalitarianism, on Segall's interpretation, is the view that "it is unjust for individuals to be worse off than others due to outcomes that it would have been unreasonable to expect them to avoid" (Segall 2010, p. 13). These outcome inequalities are the sole concern of distributive justice, and society has reason to mitigate them (Segall 2010, p. 14 and ch. 8). On the other hand, strict luck egalitarianism provides no reason to help those who are worse off than others because of unreasonable choices they made. Strict luck egalitarianism contrasts with moderate or pluralist luck egalitarianism that combines luck egalitarianism with other principles of justice (Brown 2005, pp. 307–308). The strength of luck egalitarianism is that it accounts for the way in which those who voluntarily take unreasonable risks are responsible for the ensuing burdens they suffer and the unfairness of imposing those burdens on others who have acted reasonably. A major weakness of strict luck egalitarianism, however, is that it provides no reason to aid those who suffer, however severely, as the result of their own unreasonable choices.

Shlomi Segall attempts to avoid this weakness by adopting a pluralist position and supplementing strict luck egalitarianism with the principle that the vital needs of people such as health care ought to be met (Segall 2010, pp. 68–69). Although Segall refers to this as a sufficientarian principle in Chap. 4, he also adopts a prioritarian approach to health care in Chap. 8 where he defends a modified version of luck egalitarianism that he calls luck egalitarian prioritarianism that prioritizes those who are worse off among those equally warranting assistance on grounds of luck egalitarianism (Segall 2010, pp. 112–113). According to Segall, the needs-based principle follows from the equal moral worth of individuals (Segall 2010, pp. 68–69). It also follows from the principle of equal moral worth that it is unfair for people to suffer the bad consequences of brute luck, though it does not follow, according to Segall, that the ill effects of option luck should never be mitigated. This allows the distributive principle of meeting needs to be applied in the case of option luck without undercutting luck egalitarianism, according to Segall.

I have two concerns. The first is an issue raised by Kristin Voight (2007). On the luck egalitarian principle of distribution, it appears to be fair that some suffer the ill consequences of their option luck. But then, as Kristin Voight argues, this fair distribution is upset by a sufficientarian principle of meeting basic needs (Voight 2007, pp. 403–405). An egalitarian account that did not produce such a conflict

would have an advantage, and this, I shall argue shortly, is the case with democratic equality. My second concern is that it is not clear why an adequately justified needs-based principle requires supplementation with luck egalitarianism at all. A well-justified needs-based distributive principle seems to adequately account for the bad fortune that society can justifiably be required to alleviate. To require compensation when needs are not at issue runs into the sort of counter-examples often raised against luck egalitarianism such as people who have unattractive features that could be corrected by plastic surgery (Daniels 2008, p. 72). Even if having unattractive features is unfair brute luck in some cosmic sense, it is not the sort of thing that requires inclusion in a universal health care system. Segall discusses such cases and argues that if a feature such as breasts that are too small creates serious problems of self-esteem it should be covered (Segall 2010, pp. 130–131). But in that case it could as easily be argued that it should be covered as a basic necessity in a particular culture.

It is interesting to note that Alexander Brown defends luck egalitarianism by adopting a pluralist or moderate luck egalitarian position that supplements strict luck egalitarianism with democratic equality (Brown 2005, p. 331). The problem with this approach is that democratic equality seems to be doing all the work. On Brown's version, strict luck egalitarianism is not so much supplemented as sidestepped. So why not simply accept democratic equality and be done with it?

Brown's answer is that luck egalitarianism is needed to capture our intuitions about responsibility (Brown 2005, pp. 314–319). I believe, however, that democratic equality can better capture our intuitions about responsibility. There are, of course, different senses of "responsibility" (Dworkin 2011, p. 103). We can be responsible for harm in the sense that we are morally culpable and can be blamed for the harm. In a different sense of "responsibility" we can be justifiably required to bear the burden of the harms that result from our conduct. Even regarding capabilities that are guaranteed, and hence for which people are not fully liable in the second sense of responsible, democratic equality need not deny that those who voluntarily take unreasonable risks are morally responsible in the sense of being culpable for the burdens they suffer themselves and impose on others. Nor does democratic equality deny that it is unfair for the imprudent to impose those burdens on others. Those who voluntarily engage in unreasonably risky activities are free riders on the prudence of others who ultimately need to care for them. The imprudent therefore engage in a subtle form of exploitation.

Democratic equality provides reason to mitigate this, even if the imprudent are guaranteed a certain level of access to health care. Hence, as is true with some forms of luck egalitarianism, democratic equality would also permit taxing certain dangerous products and imposing fees on risky activities as a way of alleviating the potential for exploitation of those who would otherwise bear the full burden of the harm that results. Along these lines Elizabeth Anderson claims that we can prohibit people from building in fire prone areas (Anderson 1999, p. 323, nt. 82). This does not require examination of the motives of individuals, as fees and taxes can be placed on dangerous products (e.g., firearms and cigarettes) and dangerous activities (e.g., mountain climbing and professional boxing). At the

same time democratic equality places reasonable limits on responsibility for one's health care. While holding the imprudent morally responsible and even responsible for reasonable costs of their care, it nonetheless guarantees a level of care when those who are burdened cannot afford the costs. To that extent people are not held fully liable for the harm they suffer. Democratic equality also holds individuals responsible for the cost of medical treatment that is not necessary for participation in society as free and equal citizens.

As a result, democratic equality provides a reason for individuals to care for themselves and to find ways to cover the cost of the unreasonable risks that they take. Democratic equality therefore provides both a reason for society to care for its members by providing them with guaranteed access to health care necessary for participation in society as free and equal citizens and a reason for individuals to take advantage of the available access and to care for their own health by not taking unreasonable risks.

This gives democratic equality a way to mitigate the leveling down objection that vexes some forms of egalitarianism. Democratic equality is compatible with significant inequalities in health care, as people decide whether to take advantage of their guaranteed access to health care and whether to devote private resources to health care beyond what is guaranteed. Democratic equality does not value equality for its own sake and hence does not require equality in health or health care unless the inequality is so great that it supports oppressive hierarchies. As Segall notes in a context not related to democratic equality, if some are so ill as to be unable to participate in democracy, making others equally ill does not serve the cause of democracy (Segall 2010, p. 118).

On the other hand, some forms of leveling down such as progressive income tax and luxury tax may be required to preserve the capabilities necessary for free and equal citizenship such as meaningful access to health care (Anderson 1999, p. 326). But, these are justifiable. As people profit or suffer losses from reasonable choices inequalities in society can grow to levels that adversely affect the health and well-being of all. Recent work on public health and the health gradient provides a good illustration of this. Social, economic, and environmental conditions have a tremendous impact on health. Richard Wilkinson and Kate Pickett argue in their recent book, *The Spirit Level*, that the health gradient, including life expectancy, parallels the degree of socioeconomic inequality (Wilkinson and Pickett 2009). They claim that the research provides evidence that it is inequality itself that leads to a variety of social ills such as crime, obesity, various sorts of mental and physical ill health and lowered life expectancy (Wilkinson and Pickett 2009, ch. 2). In addition, those who occupy a lower socioeconomic position have poorer health and a shorter life expectancy than those who occupy higher levels (Wilkinson and Pickett 2009, ch. 6). Wilkinson and Pickett explore various possible causal mechanisms to explain this such as levels of stress generated by inequalities and argue that reducing the degree of inequality would reduce the differences in health and life expectancies and benefit people at all levels of the socioeconomic gradient (Wilkinson and Pickett 2009, ch. 16). Democratic inequality captures our intuitions about why this is problematic and

suggests a reason why these inequalities should be reduced. The inequalities that produce differences in health status and social problems including lack of education and violence impede free and equal participation in the life of the community. It follows that democratic equality provides reason to reduce the level of socioeconomic inequality in a society when necessary to secure guaranteed capabilities include a right to health and health care.

An advantage of democratic equality over luck egalitarianism therefore is that it both captures our intuitions regarding responsibility for one's own care and avoids major problems such as tolerance for destructive inequalities based on option luck and abandonment of the imprudent.

8.4 Possible Objections

Luck egalitarians, however, have raised important objections to Anderson's democratic equality that are especially relevant to health care and end-of-life treatment. While democratic equality justifies a right to meaningful access to health care, it is arguable that such a right would have a severely limited scope. It might, for example, be argued that it is unclear on the basis of Anderson's version of democratic equality why incompetent adults and children should have a right to health care. Anderson bases democratic equality on the equality of competent adults as equal moral agents, but there are those so severely incompetent that they will never be able to participate in the community as free and equal citizens. While medication can mitigate the suffering of these people, it will not restore them to moral agency or enable them to participate in society as free and equal citizens. Anderson's democratic equality seems to have escaped the objection of abandoning the imprudent only to be faced with the objection of abandoning the incompetent.

As previously noted, it is best to modify Anderson's version of moral equality to cover moral agents generally as well as future moral agents. Another consideration is that people are more or less competent and they may be competent in some areas while lacking competence in other areas. Thus, a person may be able to participate in civic society in various ways while being incompetent to hold a steady job. In addition, people may drift in and out of competence in a particular area. As a result, it is often difficult to distinguish competent from incompetent persons. History is replete with cases of discrimination against competent adults who were judged to be feeble-minded, insane or otherwise incompetent. This is perhaps most obvious in the eugenics movement that swept much of the United States and Europe in the first half of the twentieth century. Attempting to draw lines that exclude the incompetent from health care would therefore threaten the competent as well as the incompetent. In addition, children who are not yet competent need to be covered by universal health care because they will become competent if well cared for. Health care is also necessary for effective moral agency and participation at whatever level of competence is attainable by a person.

There are also reasons based on compassion and benevolence to care for those who are incompetent, and democratic equality does not undercut these reasons. In fact, democratic equality provides support for the fostering of such virtues because of the role they play in resisting oppression. In the context of democratic equality reasons based on compassion and reasons based on fairness are compatible and not competitive. It is not so easy, however, to supplement luck egalitarianism with such care-based reasons because action to mitigate harm upsets the equality on which luck egalitarianism is grounded, just as supplementing luck egalitarianism with a needs-based principle does.

Shlomi Segall notes three additional objections that might severely limit the scope of democratic equality. First, it appears that democratic equality would not justify an entitlement to treatment for medical conditions that neither curtail the ability to resist oppressive relationships nor restrict political or civil participation (Segall 2010, p. 41). Second democratic equality is open to the objection that democratic participation as equals is compatible with everyone's living a squalid life and having significant ill health (Segall 2010, p. 38). Third democratic equality would justify health entitlements only within the context of democracies (Segall 2010, p. 41).

These problems are not as severe as might appear, however. Consider first the worry about serious medical conditions that do not curtail democratic or civic participation. The counter-example gains its force from imaging, for example, a person who is suffering from a medical condition so severely that it ought to be covered by a health care plan even though the person can still participate in society as a free and equal citizen. The problem is that conditions that cause enough suffering to enliven the counter-example also limit such participation. Keep in mind that Anderson construes democratic participation broadly to cover participation in civil society generally, including participation in the economy (Anderson 1999, p. 317).

We also need to take account of practical considerations in moving from the basic principle of democratic equality, which guarantees health care access for health conditions that limit such participation, to an enforceable health care policy. In particular, types of illnesses, disabilities and disorders need to be covered that typically limit such participation even if there are some individual cases of those maladies that are mild enough not to limit civic participation. There is reason to cover conditions such as arthritis, chronic pain, and depression because of the frequency with which they limit civic participation, especially engagement in the economy, even though there are some cases of arthritis, for example, that are bothersome without affecting such participation. Although mild conditions that typically do not affect participation as free and equal citizens will not be covered as a practical matter, special provision can be made for those rare persons whose participation is in fact limited. In general, however, health conditions that are significant enough to warrant medical help also limit some sort of functioning in one's political or civil society broadly construed.

Democratic deliberation also has a role to play. Individual societies need to design a universal health care system on the basis of what is necessary for participation in their society and on the basis of which maladies typically limit participation.

Health care resources also need to be weighed against other requirements for effective participation in society as a free and equal citizen, and this is a matter for democratic deliberation. Democratic equality allows for democratic deliberation, but specifies that participation as free and equal persons is to be the guiding principle (Anderson 1999, p. 332). When resources are scarce, for instance, those conditions that are more likely to limit participation can be given a higher priority. Participation in society, after all, is necessary for the exercise of a broad array of rights from employment to education to political rights.

This argument can also be used to deal with the objection that democratic equality is compatible with everyone living a miserable or squalid life. Consider, for instance, a community in which schistosomiasis is so prevalent that virtually all adults suffer from it. According to the objection, in spite of the pain and flu-like symptoms those who suffer the illness experience they are still able to participate in a democracy and civil society as equals because they all suffer equally. In dealing with this objection it is important to keep in mind that democratic equality is concerned with resisting oppression and exploitation as well as participating in one's community as free and equal citizen. Countries with endemic health problems that are shared by nearly all members of society find it difficult to participate as equals in the global economy, and the people in such nations are rendered vulnerable to exploitation by more wealthy nations.

There is, however, an underlying issue that needs to be dealt with. How should health care resources be allocated when funds are meager and health care resources needed to deal with maladies shared by all compete with resources needed to combat maladies that affect only some in the community? The ability of people to thrive as free and equal citizens and to resist oppression is likely to be more relevant within the context of a particular nation than the rather tenuous global community. As a result, when resources are scarce in a particular society there is reason, other things being equal, to give priority to conditions that prevent some members from participation as a free and equal citizen within that society.

Anderson is concerned with participation as equals in democratic society, and Segall's third objection is that democratic equality applies only within the context of democracies. There are two respects, however, in which democratic equality applies to non-democratic societies. First, it is even more important that people have the capabilities to resist oppression in non-democratic societies, since the potential for oppression may be higher than in democratic societies. Second, as previously noted, democratic equality can be argued in terms of community participation generally and not just political participation. Even in non-democracies, people are of equal moral worth and should be treated as equal members of the community. They have a right to be treated as equal citizens, which they do not lose because they are presently living in an undemocratic nation that fails to respect their rights. The label "democratic equality" is unfortunate in this respect, because it misleadingly connotes that the theory is restricted to equality within democracies.

In summary, democratic equality provides a justification for access to health care and is thereby able to avoid the abandonment of the imprudent objection without the need to supplement democratic equality with competing principles of

justice. Although democratic equality can be supplemented with reasons based on compassion and benevolence, these do not compete with democratic equality and are best not viewed as principles of justice in any case. While democratic equality provides reason to hold people who take unreasonable risks morally blameworthy for imposing burdens on others and to tax unreasonably dangerous products and activities, democratic equality would nonetheless hold it as a violation of their rights not to provide meaningful access to treatment. In short, defenders of democratic equality have reason to claim that democratic equality captures the central insight of luck egalitarianism regarding responsibility and fairness without the unpalatable consequences that require supplementation with competing principles of justice. In this way democratic equality justifies a duty on the part of society to care for its citizens in order to ensure the ability to participate in political and civic community life and a duty on the part of individuals to care for themselves to avoid becoming a burden on others.

8.5 Implications for End-of-Life Care

Democratic equality mandates that people be guaranteed certain capabilities, including some related to health, throughout their lives. This applies to the elderly, the very elderly and those who are terminally ill whether elderly or not. As previously noted, democratic equality is grounded in the belief that all persons are of equal moral worth. Elderly people and those who are terminally ill and receiving end-of-life care are still members of the community and of equal moral worth, according democratic equality. Moreover they can, unless disabled to the point of entirely lacking competence, continue to participate at some level in society as free and equal citizens and resist oppression. This has implications for a variety of issues, three of which I will consider: (1) rationing life-extending health care resources, (2) physician-assisted suicide, and (3) waiving the right to life-extending treatment.

8.5.1 Rationing Life-Extending Health Care

It is a sad fact that not all of the guaranteed capabilities needed to enable persons to function as free and equal democratic citizens can be fulfilled in all cases. Medical treatments that could extend life will sometimes be so costly that they undercut resources needed for other guaranteed capabilities or require transplantation of organs in short supply. The result is that some of those waiting for a scarce organ such as a heart or kidney die while still on the waiting list. If the government does not develop a rationing policy, the distribution of expensive or scarce health care resources will be allocated by some other means such as private insurance or ability to pay. One way or another, scarce and expensive resources are allocated, and this amounts to rationing, either explicit or implicit.

Democratic equality does not tell us precisely what rationing policy ought to be adopted, but it does provide useful background principles. The most important is that rationing policies need to treat people as having equal moral worth throughout the course of their lives. Democratic equality would not, for instance, countenance using criteria of social worth such as those used by the infamous Seattle Life or Death Committee set up in 1960s by the Seattle Artificial Kidney Center to determine who would have access to the newly invented dialysis machine (Alexander 1962). Democratic equality contrasts sharply with luck egalitarianism in such cases, since luck egalitarianism would require some mechanism to take into account the responsibility of the individual for his or her medical condition. One of Anderson's main objections to luck egalitarianism is the need for intrusive investigation to determine responsibility for the burdens one suffers (Anderson 1999, p. 310).

In addition, rationing decisions should be made democratically on the basis of enabling free and equal participation in community life. Democratic equality supports the view of those who argue that rationing decisions should be made at the policy level where they are open to public inputs rather than by individual doctors or health care providers even though they are the ones who apply the policy. This requires a move to explicit rationing, as opposed to the implicit rationing of the market. Democratic equality is compatible with the adoption of medical criteria for determining which treatments will be funded, as opposed to who will receive treatments. In particular, the use of quality-adjusted life years (QALYs) and cost-benefit analysis could be used as criteria. Treatments are evaluated on the basis of QALYs in terms of both how much improvement they would make for a particular sort of patient and how many additional years of life would be gained by the treatment. Treatments can then be assigned a cost per QALY for purposes of allocating resources and rationing.

Rationing on the basis of age is far more controversial, and democratic equality provides reasons for caution. In a society in which the elderly face discrimination in employment and live in a culture that is pervaded by the value of youth rationing medical care on the basis of age can exacerbate the discrimination the elderly already face. From the point of view of democratic equality, it is important to prevent age from becoming the basis of an oppressive hierarchy in which the elderly are treated as having less moral worth than the young.

Age, however, can be an indirect factor in rationing because of the way in which it might be relevant either in determining need or in calculating the likelihood of medical success. In the United States, for example, between 1997 and 2007 the 10-year patient survival rate for heart transplant recipients between the ages of 35 and 49 was 59%, while the survival rate for recipients at least 65 years old was 46.9% (U.S. Department of Health and Human Services Organ Procurement and Transportation Network 2009). In such cases age may be a factor in determining the likelihood of success of the operation, although there may be exceptions in the case of younger persons who have health problems that make success less likely. Of course, rationing sometimes favors the elderly. When flu vaccine is rare there is some reason to give preference to the elderly first who may be more likely to die from flu. Even here, however, it should be noted that younger people with chronic

lung ailments might warrant priority on the list to receive flu vaccine. Using age as one factor to determine whether treatment is medically warranted on the basis of likelihood of success should be distinguished from using age itself as a criterion for rationing. The former is justified on democratic equality, but not the latter.

It might be objected that in a situation where there are far more people needing heart transplants than there are available organs, it is simply unreasonable to transplant a heart in a 70-year old patient when it means that a 40-year old patient will die. Ronald Dworkin, for example, states that it is reasonable on grounds of fairness to save the life of one young man rather than two older men because "they have already lived substantial lives and he has not" (Dworkin 2011, p. 282). This is reasonable if we see human dignity and equality in terms of having a life as a project that one creates since the elderly have had more of a chance to succeed at their life projects. It is not so reasonable, however, if moral equality is seen in terms of being a moral agent or a potential moral agent. Also, it will not do to say that age-based rationing is reasonable because giving the younger person the transplant purchases more years of useful life. That line of argument has the unfortunate consequence that the younger a person is the more justification there is for a transplant. But, it is far less plausible to say that we should prefer a 40-year-old person to a 45-year old for purposes of a heart transplant because of a slightly longer life expectancy.

Norman Daniels provides a more plausible justification for age-based rationing of scarce health resources (Daniels 1988, ch. 5 and Daniels 2008, ch. 6). Daniels argues that we need to consider birth cohorts, rather than age groups. Age groups are groups of people at various ages (30-year olds, 40-year olds, etc.). Birth cohorts are groups born at the same time. Birth cohorts move through all of the different age groupings together (Daniels 1988, pp. 12–14). Age-based rationing can be given a contractualist justification, according to Daniels, if we take account of birth cohorts (Daniels 1988, pp. 85–91). Daniels adopts what he calls the "prudential lifespan account" and asks what prudent deliberators would decide for distribution of medical resources over the course of their lives if they did not know their age or view of the good life (Daniels 1988, pp. 56–63). People who deliberate under these constraints have reason to prefer that scarce medical resources be given to the young so that they will increase their chance of living a normal lifespan (Daniels 1988, pp. 53 and 86). On Daniels's view, this is not unjust age discrimination because people who live a normal lifespan go through all of the stages of life as a cohort. As long as birth cohorts are treated equally from one generation to the next, rationing based on age need not be unjust (Daniels 1988, p. 98). This does not eliminate the charge that age-based rationing is unjust discrimination, however. It is true that it would be prudent for a person behind Daniels's version of the veil of ignorance to design health policies that maximize the potential for a normal lifespan including rationing of scarce health care resources based on age. It does not follow, however, that it is the best policy for an actual community dealing with issues of age discrimination. Justice is not to be grounded ultimately in prudence, according to democratic equality.

Since, on democratic equality, all persons have equal moral worth regardless of their age, they do not lose the right to needed medical care because they have

become elderly. As a result, when organs are scarce they should be allocated on the basis of criteria related to medical diagnosis and prognosis. Moreover, they should not be allocated on the basis of criteria that exacerbate already existing patterns of discrimination. As previously noted, there may be medical reasons based on such factors as 5-year survival rates to give an organ to a person who is 45 rather than 70, but age itself is not to be appealed to as the deciding factor.

8.5.2 Physician-Assisted Suicide

A variety of reasons have been offered for prohibiting physician-assisted suicide. Those who oppose it offer a variety of reasons including the basis of the state's interest in life, the sacredness of life, and potential harm to the reputation of the medical profession. Those who argue in favor of assisted suicide often appeal to the value of ending suffering or to individual autonomy. Democratic equality offers further support for autonomy-based arguments in support of the right to assisted suicide. According to democratic equality, policies regulating assisted suicide should be evaluated in large part on the basis of what sort of legislation is necessary to enable individuals to resist oppression. Certainly it is a form of oppression to be coerced or manipulated into living or dying on the basis of values that one does not share. Thus, democratic equality provides a fairness-based reason to adopt standards that ensure that people will be able to freely choose whether to forgo life-extending treatment or even to seek assisted suicide. At the same time, however, democratic equality provides strong reason to adopt adequate safeguards to ensure that people are not forced into refusing medical care or opting for assisted suicide.

It is also important that democratic equality provides reason to supply those who are approaching the end of life with sufficient medical resources that they are not driven into refusing available life-extending treatment or, if legal, physician-assisted suicide to avoid treatable pain and suffering or becoming a burden. This includes providing access to a range of comfort care including effective analgesics and mental health therapy. It also includes providing access to life-extending medical treatment provided that it is not ruled out by the necessity of a justifiable rationing scheme. Over a third of those seeking lethal medication under Oregon's Death with Dignity Act cited the desire to avoid being a burden on friends and family as a reason for their request, and 3% citied the cost of medical treatment (Oregon Department of Health and Human Services 2006, p. 23). This is a serious problem, especially in the United States where severe illness can bankrupt a family. Family caregivers also experience significant stress and often suffer health-related problems. There are good reasons based on democratic equality for providing enough health care that those who care for family members approaching death will not be physically, financially and emotionally exhausted and will have sufficient capabilities for functioning as free and equal citizens. While democratic equality guarantees access to the sorts of medical resources that might reduce the motivation for physician-assisted death, it also provides strong reasons to adopt safeguards to ensure that

people are not manipulated into choosing to die, whether by refusing treatment or assisted suicide.

This contrasts with some forms of luck egalitarianism. Those who are denied resources from society because their misfortune is the result of bad option luck may end up seeking assisted suicide when they otherwise would have continued to live. To avoid this problem luck egalitarianism needs to be supplemented with another principle such as meeting basic needs or democratic equality itself. But these additional principles tend to simply supplant or even undermine luck egalitarianism, as was previously argued.

8.5.3 Relinquishing the Right to Health Care

It might be argued that people should be able to permanently waive or relinquish their right to health care. Some might want to do this so that they can take unreasonable risks without having to pay a fee or becoming a burden to caregivers. Others might also be willing to forgo the right to health care in order to avoid having to pay taxes or insurance premiums. This is compatible with luck egalitarianism, but in the case of life-extending treatment and treatment necessary to prevent severe suffering it is not compatible with democratic equality. Shlomi Segall advocates a system of universal health care that one cannot opt out of or waive one's right to health care coverage. This is grounded in his supplementary principle of a duty to meet basic needs, however, not in luck egalitarianism (Segall 2010, ch. 5). According to Segall, coverage for basic needs including health care cannot be waived, but we should not force treatment on people (Segall 2010, p. 78). This reflects Joel Feinberg's distinction between waiving the exercise of a right on a particular occasion and permanently relinquishing the right (Feinberg 1978, pp. 120–123).

Anderson also holds that the access to basic health care cannot be permanently waived, although she offers a quite different argument. Put in terms of rights, democratic equality distinguishes permanently waiving or relinquishing the right to health care along with its corresponding duty from merely declining the health care that is offered. It holds, in short, that rights to capabilities needed to secure free and equal citizen, including the right to health care, are inalienable. Anderson briefly argues for this by saying that we cannot ignore those with severe health needs because they have moral worth that no one can disregard (Anderson 1999, p. 330). More needs to be said, however. It is certainly true that we cannot ignore the moral worth of people, but what does it mean to respect moral worth? It might be argued, given the centrality of moral agency to democratic equality, that this means that we need to respect their moral agency and hence their choices. We allow people to limit future liberty in a variety of contexts such as employment contracts and other long-term contracts, however. Why not also allow them to limit future health care guarantees by relinquishing the right to health care, especially when the risks are low and the treatment is expensive? If respecting a person's moral worth means respecting his or her choices, including the right to refuse needed health care, then it is arguable that

this should also include respecting an autonomous decision to relinquish the right to health care. On the other hand, if respecting a person's autonomy means protecting the ability to make autonomous choices, then it is not clear that we should allow a person to refuse life-extending medical treatment that, after all, preserves autonomy. To avoid this dilemma and still defend democratic equality, we need a different argument.

There are certainly good reasons based on democratic equality to allow someone to refuse medical care on a particular occasion. To respect a person's moral worth is, in part, to respect the free and informed choices the person makes, and sometimes a person has very good reason to refuse life-extending medical treatment. Such treatment may, for instance, only prolong the dying process or lead to unbearable suffering. There are also reasons for limiting future medical care in some cases. Advance directives, for instance, can limit medical care in the event one becomes incompetent. The right to medical care is not permanently waived or relinquished in such cases, however, because it can be reasserted and life-extending care can later be demanded, and advance directives can be revised.

None of this justifies permitting permanent waiver of the right to life-extending treatment, according to the tenets of democratic equality. At the outset it needs to be noted that people change, often radically. As Derek Parfit points out, the youth who smokes may be virtually a different person from the older adult who gets cancer (Parfit 1984, section 106). Respect for moral agency requires respecting the choices that are made by the adult as well as the choices made earlier in life. In effect, the youth who permanently waives the right to medical care is not respecting his or her future self. This lack of respect should not be reinforced by society's refusal to offer care on the basis of the decisions of the youth.

It should also be noted that permanent waiver of the right to receive medical care necessary for avoiding severe suffering or death places a heavy burden on others, even if not a financial burden. Not offering help to those who are suffering or dying requires a degree of hardness that undercuts virtues such as compassion and benevolence, and it is in the interest of society to foster such virtues. The situation is different when someone refuses care that is made available and offered. In that case those offering care need to respect the choice of the potential recipient, and the fact that the offer remains open is compatible with benevolence and requires far less hardening on the part of others.

The duty of society to provide access to health care can also be defended by appealing directly to the tenets of democratic equality. Even if it is based on a person's prior choice, to permanently deny the person's requested access to care needed to participate in society as a free and equal citizen when it is not justified by rationing is to consign that person to second-class citizenship. Hence democratic equality justifies the claim that society ought to provide meaningful access to health care whether or not people are viewed as having a right to that health care. This differs from the person who renounces his or her citizenship altogether and is no longer a member of that society. Those who renounce their citizenship are not second-class citizens; they are not citizens at all in that society.

There is reason, then, to suppose that even if the right to life-saving health care could be relinquished society ought, nonetheless, to guarantee access to life-saving health care. It is just that it would not be based on a right to health care. If it assumed that the right to life-saving health care could be relinquished, what would be relinquished is the moral status of being able to demand performance on the duty to provide access to the needed health care. The duty remains, but the right-holder moves from being a person to whom the duty is owed to being merely a person who is the object of the duty. From the point of view of democratic equality, one would no longer have the status of moral equality with those who had not relinquished their right because one would no longer be in a position to demand a capability necessary to functioning as an equal citizen (Feinberg 1970, p. 252). So we are again faced with worries about second-class citizenship. It follows that the right to life-extending health care cannot be permanently waived or relinquished. The right to life-extending health care is inalienable, though not inviolable.

8.6 Conclusion

Democratic equality has much to recommend it. It is able to capture some of the intuitively appealing features of luck egalitarianism regarding responsibility and fairness while avoiding some of the problems such as abandoning the imprudent. It is a stronger theory than objections raised by luck egalitarians indicate. Moreover, democratic equality has important things to say about health care in general and end-of-life care in particular.

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