

JUST SOLIDARITY: THE KEY TO FAIR HEALTH CARE RATIONING

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Abstract. I agree with Professor ter Meulen that there is no need to make a forced choice between “justice” and “solidarity” when it comes to determining what should count as fair access to needed health care. But he also asserts that solidarity is more fundamental than justice. That claim needs critical assessment. Ter Meulen recognizes that the concept of solidarity has been criticized for being excessively vague. He addresses this criticism by introducing the more precise notion of “humanitarian solidarity.” However, I argue that these notions are still not precise enough and are in need of behavioral translation, especially in relation to the problem of fair health care rationing. More specifically, I argue that translation ought to take the form of a well-ordered process of rational democratic deliberation, which I describe and defend in this essay. Such a process is what is required to construct a working model of *just solidarity* as opposed to a merely abstract idealization of just solidarity.

Keywords: solidarity, humanitarian solidarity, health care rationing, justice, rational democratic deliberation, just caring, public reason, veil of ignorance.

Let me begin by saying that I fundamentally agree with Professor ter Meulen that there is no need to make a forced choice between “justice” and “solidarity” when it comes to determining what should count as fair access to needed health care.¹ Ter Meulen also wants to assert that solidarity is more fundamental than justice. This is a point I believe needs critical analysis, which will be the primary goal of this commentary. Ter Meulen recognizes that the concept of solidarity has been criticized for being excessively vague. He tries to address this criticism by introducing the more precise notions of “reflective solidarity” and “humanitarian solidarity.” However, I will argue that these notions are still not precise enough and are in need of behavioral translation, especially in relation to the problem of fair health care rationing. More specifically, I will argue that translation ought to take the form of a well-ordered process of rational democratic deliberation. In my own work I have referred to the problem of health care rationing as

¹ Meulen [2015].

the “Just Caring” problem: What does it mean to be a “just” and “caring” society when we have only limited resources (tax dollars or health insurance dollars) to meet virtually unlimited health care needs?²

The basic implication of the “Just Caring” problem is that the need for health care rationing is inescapable. In other words, some range of health care needs will not be met. Some individuals will need to be told that they will not be provided with a \$100,000 cancer drug for their metastatic cancer because the drug will likely yield for them only two extra months of life. Other individuals will be told that they will not be provided with a \$200,000 Left Ventricular Assist Device [LVAD] for their end-stage heart disease because they are already eighty-five years old and this device will likely add only another year of somewhat diminished quality to their life. Still other individuals will be denied a \$40,000 Implantable Cardiac Defibrillator [ICD] because our best medical judgment is that there is less than a 3% chance that they will experience a fatal cardiac arrhythmia in the next two years. No one can blame any of these individuals if they offer some snide or sarcastic response when they are reminded that they are part of a society for which commitment to solidarity is a fundamental value: “If this is what solidarity is supposed to mean, then I would prefer to live alone on an island than to die in solidarity.” In health care the problem of health care rationing is the most fundamental challenge that proponents of the virtue of solidarity must be prepared to address.

To be clear, no Western nation can claim that the financial resources are unavailable to underwrite the costs of a few thousand of these cancer drugs, or a few thousand LVADs or ICDs. But the need is potentially much greater than that. About 600,000 Americans die of cancer each year and 1.3 million citizens of the European Union have the same fate. About 500,000 Americans die of heart failure each year and the same will be true for about one million citizens of the European Union. If all of these individuals had an equally just claim to these two interventions (because of a commitment to solidarity) the annual increase in health costs in the US would be about \$100 billion while in the European Union the cost would be about €200 billion.

The problem, as a prescient Daniel Callahan noted long ago,³ is that what we regard as justice-relevant health care needs are tied inextricably to advancing medical technologies. There was no pre-existing need for LVADs or ICDs or bypass surgery before these interventions were invented. More than anything else,

² Fleck [2009].

³ Callahan [1990].

emerging medical technologies in every area of medicine have driven the problem of escalating health care costs followed by the need for health care cost containment, i.e., health care rationing. This is why in the United States we have seen the share of GDP devoted to health care rise from 5.2% in 1960 to about 17.6% in 2014 with projections of 20% by 2022.⁴ The escalation curve in the European Union has not been as steep but the perceived need to control health care costs is seen as being just as urgent. The successful dissemination of costly life-prolonging medical technologies contributes to the growth of an aging population with more costly chronic conditions in both Europe and the United States. In the United States, for example, 23% of our Medicare population (those over age 65) has five or more chronic conditions.⁵ Further, 10% of our Medicare population will consume 58% of Medicare dollars in any given year, roughly \$375 billion out of \$640 billion in 2014.⁶ It seems reasonable to describe that 10% as being among the “medically least well off,” that is, those who are most deserving of social compassion. But if there is a social need to control health care costs, then it seems reasonable to begin where there are the greatest expenditures, namely, among those who are medically least well off. But how can that political/economic imperative be made compatible with a normative commitment to what ter Meulen refers to as “humanitarian solidarity”?

Ter Meulen describes humanitarian solidarity as ‘a solidarity that takes responsibility for the existence of the other who is not able any more to take care of himself or herself.’ He adds that it is a *humanitarian* solidarity ‘because it is not a solidarity based on personal interest but on identification with the values of humanity and responsibility for the other.’⁷ That is, we are all capable of understanding that their fate could be our fate as well. But then ter Meulen goes on to note that increasing health care costs (in Europe) are eroding a public commitment to this understanding of solidarity. Taxes paid to support the health care system are regarded as an “investment” for which individuals hope to get an adequate return in the form of access to any and all effective health care they might need in the future. Thus, if individuals have been quite healthy for the vast majority of their life, they will hardly be receptive to being told they will be denied a \$100,000 cancer drug because it will only yield four additional months of life with their cancer. They will feel instead that they have already paid for it with decades of health care

⁴ Sisko et al. [2014].

⁵ Thorpe [2010].

⁶ Schoenman [2012].

⁷ Meulen [2015] p. 5.

taxes or premiums. Likewise, if these same individuals have been attentive to their health but see others adopting unhealthy life styles that generate costly health needs that more health conscious individuals must pay for as well, then this too will be a reason for rejecting solidarity as a basic social value if irresponsible health conduct is supported by that value. I have no doubt that these are accurate descriptions of a sociological and political phenomenon in both Europe and the United States. The practical normative question is what counts as a suitable response to this phenomenon, especially in light of the inescapability of the problem of health care rationing.

Ter Meulen claims that solidarity, thought of as humanitarian benevolence, ought to be seen as foundational to justice, as opposed to the Rawlsian view that sees justice as the first virtue of society.⁸ He endorses the views of Michael Sandel, who sees relations within a well-functioning family as something that ought to be mimicked in society at large.⁹ In a well-functioning family, individuals are very sensitive to the needs of each other and generously responsive in attempting to satisfy those needs. When family members start insisting on getting their fair share, something has gone awry according to Sandel. Ter Meulen adds that in such a situation 'justice may become very calculating about what is just, instead of being humane and gentle.'¹⁰ For him, this sense of justice is lacking in compassion. The critical question I want to raise, however, is whether compassion, untethered from a sense of justice, is something that should be seen as socially virtuous.

While compassion or benevolence might be seen as being ethically obligatory in some circumstances, ter Meulen would see that as a reflection of a Kantian ethical perspective rather than his preferred Hegelian understanding of ethics. This suggests that compassion is something that is freely given; it is an expression of generosity, not niggardly duty. Such magnanimity certainly merits social approval, in part because it is freely given. But it is noteworthy that what is freely given belongs to the individual doing the giving. Imagine, by way of contrast, the following scenario.

I belong to a congregation that seeks to be sensitive to the health care needs of its members. We count on the pastor to become cognizant of these needs and to bring them to the attention of the congregation as a whole. One member of the congregation, Abe, is uninsured and in need of \$100,000 surgery in order to save

⁸ Rawls [1971].

⁹ Sandel [1998].

¹⁰ Meulen [2015] p. 13.

his life. He is a very gregarious individual and knows the vast majority of the members of that congregation. Betty is in a similar situation, uninsured and needing a \$50,000 surgery in order to save her life. She is more quiet and reserved. She has only a few close friends in the congregation. She is ten years older than Abe. Her medical circumstances are such that she will only gain two extra years of life from the surgery, whereas Abe would very likely gain twenty extra years of life from the surgery. Without the surgery both would be dead in two months. Abe belongs to the racial majority in that congregation whereas Betty belongs to the racial minority.

The pastor is perplexed about what to recommend. What he knows is that the congregation could probably raise \$100,000 but no more than that for this purpose because the congregation has a number of other longstanding charitable commitments. He will do whatever the congregation decides. Imagine the following possible outcomes. Members of the congregation speak loudly and enthusiastically for Abe; he is well-known and very likeable. He gets the money. Is this an ethically unproblematic outcome because this is how the congregation chose to exercise their compassion? Alternatively, a majority of members of the congregation want to constrain what they see as excessive generosity. They support Betty because she will cost them less. She gets the money. Is this an ethically unproblematic outcome because the congregation still was compassionate, though in a more constrained fashion? Or would they be open to justified moral criticism because they “could have” been more compassionate? Or, for a third scenario, the congregation was almost evenly divided (45%–45%), each side weighing different considerations differently, but the middle 10% favored Abe because he was a member of the racial majority, just like them. Should this outcome be regarded as being ethically acceptable, all things considered, because it is still a compassionate act? Or, for a fourth scenario, it is a year later and we have Charles and Deborah. Their medical and social circumstances are essentially the same as Abe and Betty, except that Charles has a predicted survival of six years while Deborah has a predicted survival of only four years. The congregation chooses Charles because he will survive longer, though in the earlier scenario they chose Betty because she would cost them less. Should this outcome be judged to be morally unproblematic because it was a freely chosen compassionate act? Is ethical consistency a reasonable requirement when it comes to assessing acts of compassion? The primary question I ask the reader to ponder is whether concerns about justice are entirely irrelevant to all of the above scenarios.

The scenarios above have all the flaws associated with philosophic artificiality. So I will offer a real world example instead. Renal dialysis was perfected in the

late 1960s, but it was extraordinarily expensive. In constant 2014 dollars the annual cost of dialysis then would have been about \$90,000. Only a tiny percentage of these patients could afford that cost. Consequently, thousands of these patients died every year, though there was a technology there that could prolong their lives for many years. The US Congress took that as an intolerable state of affairs and passed the 1972 End-Stage Renal Disease amendments to the Medicare program. Those amendments provided complete public funding for dialysis and renal transplantation. Insurance status, financial status, employment status, age – all were irrelevant for purposes of eligibility for this funding. This was an act of pure public compassion.¹¹ However, it was not long before patients in heart failure and liver failure needing very expensive transplants asked the federal government to fund their transplants as well. They were equally deserving of compassion and were equally faced with premature death if no financial help were offered. In effect, they asked the reasonable question: “Why should the federal government bestow its largesse on patients needing kidney transplants but not patients needing liver or heart transplants?” The same problem arose for patients who were hemophiliacs, some of whom needed as much as \$100,000 worth of Factor VIII in a year to prevent their bleeding to death. They too wondered why federal compassion and largesse did not extend to them as well, especially since, on average, they represented a younger population than patients in end-stage renal failure.

Perhaps the argument could be made successfully that the Congressional decision to fund dialysis and kidney transplants alone, but not other transplants or hemophilia treatments, was not unjust, was not open to justified moral criticism. That conclusion would still support my point, namely, that acts of health care compassion are not necessarily above or beyond critical consideration from the perspective of health care justice. In other words, acts of compassion are not intrinsically self-justifying, especially when social or public resources are the means through which those compassionate acts are carried out. This would seem to suggest either that justice should be seen as being ethically fundamental to compassion, or that social compassion must be ethically constrained by relevant considerations of justice, certainly with regard to the problem of health care rationing. If solidarity is about humanitarian benevolence, then the concept that we need to address fairly and adequately the problem of health care rationing is the notion of *just solidarity*.

One way of thinking about the problem of health care rationing is from the perspective of lifeboat ethics. We have only limited resources to meet unlimited

¹¹ Rettig [2011].

health care needs; we have too many people in the lifeboat. All will perish if we allow irrational sentiment to dictate a course of action. So we need to throw out of the lifeboat the old and the very ill, those who will consume the most resources because they are the medically least well off. Obviously, this is the antithesis of what solidarity is supposed to be, much less *just solidarity*. But if health care rationing necessarily means denying some individuals, perhaps having to face metastatic terminal cancer, extraordinarily expensive drugs that will only marginally prolong their lives, then how can such a situation be seen as being congruent with the notion of humanitarian solidarity? This is where some very difficult political work needs to be done.

The notions of humanitarian solidarity and just solidarity are in reality vague, abstract idealizations that have little in the way of ethical substance. This is something that needs to be constructed through well-ordered processes of rational democratic deliberation. I can only sketch what I have in mind here. The interested reader should consult some of my other publications where I have presented this view more expansively.¹²

First, we have to start with the recognition that there are a number of reasonable theories of health care justice. For the sake of brevity, I will simply identify them as utilitarian, moderate egalitarian, strict egalitarian, prioritarian, sufficientarian, libertarian, and fair equality of opportunity. Each of these theories calls attention to a relevant and legitimate consideration of health care justice. Their proponents may sometimes believe that their theory can address all the problems of health care justice that might arise in a contemporary health care system. They are misguided in believing this. The problems of health care justice with which we are faced are most often too complex to be that simply resolved. Rawls is correct to remind us that in a liberal pluralistic society the “burdens of judgment” are such that no moral theory will have the intellectual resources to yield the fine-grained balancing judgments required by the intricacies and complexities of real world problems of health care justice.¹³ This is a role for public reason and public deliberation.

Second, ideally all need to be part of the deliberative process, even though efficiency will require that some sort of representational system make actual decisions. “All” can mean all who participate in a national health insurance scheme or all who are part of a more regional insurance scheme or sickness fund (*Krankenkasse*). Rawls invokes the notion of a “veil of ignorance” to assure impar-

¹² Fleck [2009] ch. 5, [2012].

¹³ Rawls [1993].

tiality in choosing principles of justice. Critics often deride the unreality of that notion. However, the veil of ignorance is perfectly real and relevant when it comes to the deliberative process I have in mind for addressing the problem of health care rationing. For the vast majority of us at any point in our lives we are entirely ignorant of the health-related disorders with which we might be afflicted. That provides a suitable environment for rational, objective, impartial thinking about specific health care rationing problems. Further, even if I have had a heart attack and might be initially biased toward more funding for heart-related health care interventions that most would regard as not being very cost-effective, I can be reminded through the deliberative process that I am still vulnerable to many other threats to my life and my health other than cardiac problems. I would also be reminded through the deliberative process that there are many other people to whom I am emotionally connected. Consequently, I would want to make with my fellow deliberators the fairest and most prudent choices possible, given that we have only limited resources and virtually unlimited health care needs. Put another way, the deliberative process need not degenerate into competing interest groups. Instead, we are all capable of recognizing that we are largely incapable of taking complete responsibility for meeting our health care needs; we all need to take responsibility for each other, given the uncertainty and complexity of future possible health needs.

Third, given a society committed to accepting a reasonable pluralism, it will rarely be the case for any particular rationing problem that there will be one “most just” choice that all reasonable persons would recognize. The more common situation will involve several possible choices that might all be regarded as being “just enough” or non-ideally just (along with other possibilities that would not be “just enough”). The goal of the deliberative process would be to legitimate a choice that would be “just enough” and “not reasonably rejectable” by those who might have favored a different option. This is how solidarity is constructed, at least in this area of public concern.

My critic might say that if there are several options that are all “just enough,” then why not allow each health care institution to choose whichever option or options appeal to them for whatever reason. However, there would be two problems with that criticism. First, the primary purpose of the deliberative process would be undermined, namely, individuals choosing freely in concert with others’ rationing protocols that they were willing to accept for their future possible selves. In my critic’s scenario some other institution would be making such choices for whatever their purposes might be. The result would be an imposition of these protocols rather than a free and rational acceptance by individuals affected by them.

Second, ethical consistency would be threatened under this scenario, which would threaten to fragment the solidarity that is supposed to be built through this process. For example, we could adopt a rationing protocol regarding individuals in end-stage heart failure that would not provide LVADs to those over age 75 at social expense. Or we could choose age 80 instead. Either choice might be “just enough.” But it would not be “just enough” if some hospitals or health plans would sometimes follow the age 75 protocol and at other times follow the age 80 protocol. That would introduce an element of unjust arbitrariness in actual practice.

Fourth, the most critical element in the deliberative process is respect for reciprocity. More specifically, whatever rationing protocols I would regard as just and reasonable would necessarily be protocols I would be willing to accept for my future possible self. If I would endorse a rationing protocol that would deny an LVAD or a \$100,000 cancer drug to someone over age 80 who was afflicted with moderate and progressing dementia (as well as end-stage heart disease or metastatic lung cancer), then I am ethically bound to accept that rationing protocol for my future possible self if I were in similar clinical circumstances. This is a concrete recognition of what is required by political and moral equality as well as fair and responsible solidarity. These are choices that are freely made through the deliberative process.

Fifth, what precisely does “just solidarity” require when it comes to taking responsibility for those who are medically least well off at the same time that we must make rationing decisions? How do we avoid an instantiation of “just policies” in this regard that are actually ethically indecent, completely lacking in compassion for the sake of “just efficiency”? As I have argued elsewhere,¹⁴ the medically least well off are a very heterogeneous lot. Some will be capable of full recovery; others (spinal cord injuries) will be capable of some functional recovery and will require lifelong support; still others will have an irreversible terminal illness for which very costly marginal prolongations of life might be possible. All are entitled to respectful and responsible care, the effective management of a range of quality of life diminishing symptoms. But such responsible caring does not necessarily include unlimited access to very expensive, marginally beneficial medical interventions that might do little more than prolong the process of dying.

Providing unlimited terminal care represents a misguided form of compassion that is neither just nor responsible. Very often providing such care, especially in socially visible ways, hides from social recognition unnecessary premature

¹⁴ Fleck [2011].

deaths that could have been prevented through a more just distribution of limited health care resources. In the United States, for example, where we still have at least 40 million uninsured individuals, it is estimated that there are at least 22,000 deaths annually among the uninsured that are directly related to the fact that these individuals were unable to obtain needed medical care at an earlier point in time when a detectable treatable cancer, for example, went untreated and became an untreatable terminal cancer. Those deaths are not correctly described as being merely unfortunate; they are unjust. Certainly one of the goals of the deliberative process would be to make visible situations such as this that otherwise escape social recognition and legitimate moral criticism.

Solidarity is supposed to be about taking responsibility for all. It must be about *reciprocal* responsibility; this is what builds the bonds of solidarity. Thus, if the need for health care rationing is inescapable, then it must not be the case that only the medically least well off bear the risks and burdens of rationing. The relatively healthy must be just as willing to forego marginally beneficial health care that is likely to yield very little in the way of health benefit, for example, the vast numbers of excess CT, MRI, and PET scans that are done in the United States each year, which collectively represent tens of billions of dollars of unnecessary (and unjust) health care. There are literally hundreds of these examples that ought to be critically considered through the deliberative process I am recommending. Such a process is what is required to construct a working model of *just solidarity* as opposed to a merely abstract idealization of just solidarity.

References

- Callahan [1990] – D. Callahan, *What Kind of Life: The Limits of Medical Progress*, Simon and Schuster, New York 1990.
- Fleck [2009] – L. Fleck, *Just Caring: Health Care Rationing and Democratic Deliberation*, Oxford University Press, New York 2009.
- Fleck [2011] – L. Fleck, “Just Caring: Health Care Rationing, Terminal Illness, and the Medically Least Well Off,” *Journal of Law, Medicine, and Ethics* (39) 2011, p. 156–171.
- Fleck [2012] – L. Fleck, “Just Caring: In Defense of the Role of Rational Democratic Deliberation in Health Care Rationing and Priority-Setting,” [in:] Andre den Exeter and Martin Buijsen (eds.), *Rationing Health Care: Hard Choices and Unavoidable Trade-Offs*, Maklu Press, Antwerp, p. 19–36.
- Meulen [2015] – R. ter Meulen, “Solidarity and Justice in Health Care: A Comparative Analysis,” *Diametros* (43) 2015, p. 1–20.
- Rawls [1971] – J. Rawls, *A Theory of Justice*, Harvard University Press, Cambridge, MA 1971.

- Rawls [1993] – J. Rawls, *Political Liberalism*, Columbia University Press, New York 1993.
- Rettig [2011] – R. Rettig, “Special Treatment – The Story of Medicare’s ESRD Entitlement,” *New England Journal of Medicine* (364) 2011, p. 1582–1584.
- Sandel [1998] – M. Sandel, *Liberalism and the Limits of Justice*, 2nd edition, Cambridge University Press, Cambridge 1998.
- Schoenman [2012] – J. Schoenman, “The Concentration of Health Care Spending: NICHM Foundation Data Brief,” URL = <http://www.nihcm.org/component/content/article/326-publications-health-care-spending/679-the-concentration-of-health-care-spending> [31.01.2015].
- Sisko et al. [2014] – A. Sisko, S. Keehan, G. Cuckler, A. Madison, S. Smith, et al., “National Health Expenditure Projections, 2013–23: Faster Growth Expected with Expanded Coverage and Improving Economy,” *Health Affairs* (33) 2014, p. 1841–1850.
- Thorpe [2010] – K. Thorpe, L. Ogden, K. Galactionova, “Chronic Conditions Account for Rise in Medicare Spending from 1987 to 2006,” *Health Affairs* (29) 2010, p. 718–724.