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RAWLSIAN JUSTICE AND PALLIATIVE CARE*

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ABSTRACT

Palliative care serves both as an integrated part of treatment and as a last effort to care for those we cannot cure. The extent to which palliative care should be provided and our reasons for doing so have been curiously overlooked in the debate about distributive justice in health and health care. We argue that one prominent approach, the Rawlsian approach developed by Norman Daniels, is unable to provide such reasons and such care. This is because of a central feature in Daniels’ account, namely that care should be provided to restore people’s opportunities. Daniels view is both unable to provide pain relief to those who need it as a supplement to treatment and without justice-based reasons to provide palliative care to those whose opportunities cannot be restored. We conclude that this makes Daniels’ framework much less attractive.

I. INTRODUCTION

Arguably the most prominent theory of distributive justice is that developed by John Rawls. His concern is with the distribution of primary goods, understood as ‘things which it is supposed a man wants whatever else he wants’. Rawls is specifically focused on ‘the chief primary goods at the disposition of society’, which are ‘rights, liberties, and

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opportunities, and income and wealth’ and ‘the social bases of self-respect’. The focus on social primary goods prompted critiques pointing out that this is unfair towards people who are disadvantaged in their natural characteristics. This critique is especially relevant in the area of health and healthcare, which Rawls says little about.

In his introduction to Political Liberalism he suggest that ‘[b]asic health care assured all citizens’ is an ‘institution required for ... stability’. But given that political stability is consistent with low levels of health care coverage, this is hardly an adequate reason to supply it. Elsewhere Rawls leaves decisions over the provision of healthcare to the legislative stage.

Though acknowledging such shortfalls in Rawls’ work, Norman Daniels maintained that ‘[p]roperly extended, Rawls’ theory captures just the structure of our responses [to inequalities in capabilities sets] in a plausible way’. This article sets out to consider this extension in the context of the pain relieving practices known as palliative care. This is an increasingly important aspect of contemporary health care.

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WHO defines palliative care as: ‘an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering’. The importance of palliative care is acknowledged in a wide variety of situations. But despite growing importance for medical practice, little theoretical work has been done to integrate the idea into work on distributive justice in health and healthcare. Addressing this very issue, the article brings an important practical aspect into the discussion of the most prominent theory of distributive justice in medical ethics.

It does so by first presenting Daniels’ now famous account of Rawlsian justice in health and healthcare. Afterwards it raises two criticism of this position in relation to palliative care. One is that Daniels’ account is indifferent toward the pain associated with treatment and unable to prefer the less painful of two equally effective treatments. The other is that when little or nothing can be done in terms of treatment, Daniels view doesn’t give us good reason to relieve people’s pain. In both discussions several proposals for maintaining Daniels view are discussed, including a recent argument for the viability of Daniels’ account in relation to palliative care. We also consider responses suggested by the wider Rawlsian literature. Finding none of these persuasive, we conclude that on account of its inability to provide convincing answers in relation to this important topic, the Rawlsian enterprise loses much of its appeal in a health context.

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13 Blinderman, op. cit note 12.
II: DANIELS’ EXTENSION OF THE RAWLSIAN ACCOUNT

Daniels’ account is the most developed Rawlsian position in relation to health and healthcare. Furthermore, Rawls endorses this view on several occasions.\(^{14}\) Thus, Daniels’ account is the natural starting point for a discussion of Rawlsian justice in palliative care. Daniels admits that ‘Rawls’s index of primary goods seems to be too truncated once we drop the assumption that all people are normal. People with equal indices will not have equally good life prospects if they have different health-care needs’.\(^{15}\) To cater for this shortfall Daniels extends Rawls’ theory by including the institutions protecting people’s health among society’s basic institutions aimed at providing fair equality of opportunity.\(^{16}\)

To see why, we must consider Daniels’ view on health. Daniels understands health deficits as deviations from normal functioning. Normal functioning for an individual is ‘the subset of the normal range their skills and talents make it reasonable for them to pursue’.\(^{17}\) Health needs are defined objectively as ‘those things we need in order to maintain, restore or provide functional equivalents (where possible) to normal species functioning (for the appropriate reference class by gender and age)’.\(^{18}\) Daniels then ‘emphasize[s] a relationship between normal functioning and opportunity, one of the primary social goods’.\(^{19}\) If health deficits impede people’s opportunities then the institutions tasked with providing such opportunities should also restore people to

\(^{16}\) Daniels, Just Health Care: 45; Daniels, Just Health: 57. For critiques of this application of Rawls, see F. M. Kamm. Health and Equality of Opportunity. The American Journal of Bioethics 2001: 1: 17–19.
\(^{17}\) Daniels, Just Health Care: 108.
\(^{18}\) Ibid., 32; Daniels, Just Health: 42.
normal functioning. Thus, according to Daniels, the prominence and importance of health arises through its impact on people’s opportunities.\textsuperscript{20} The relation between health and opportunities does not rely on the specification of health as normal functioning (as long as health deficits reduce opportunities). So even though much criticism of Daniels revolves around the plausibility of his view on health, this article does not dwell on that discussion.\textsuperscript{21} The above formulations are more or less consistently expressed throughout Daniels’ work. The most important recent development has been Daniels’ effort to underscore how health is influenced by social determinants outside what is traditionally understood as health care \textsuperscript{22} and to develop a procedural answer\textsuperscript{23} on how to distribute resources when reasonable persons could disagree over whom to give priority to in a world of scarce resources.\textsuperscript{24} We now turn to how Daniels’ extension of the Rawlsian approach fares in relation to palliative care.

III. RAWLSIAN PALLIATIVE CARE

The starting point for the discussion of Daniels’ view is that it has a clear focus on opportunities rather than wellbeing. Intuitively and certainly in relation to palliative care the impact of health on our life-plans and opportunities might be considered as a strange reason to provide care. Wouldn’t wellbeing on some dimension provide a more sensible rationale?\textsuperscript{25} Rawlsians, however, do not have this individualistic conception of the aim of society. For them, the restoration of normal functioning is a compelling

\begin{itemize}
  \item Daniels, Justice, Health, and Healthcare: 3,4.
  \item Daniels, Justice, Health, and Healthcare: 2; Daniels, Just Health: 12, 17, 42.
  \item While the former is widely accepted as an important development, the latter has been criticized; see A. Friedman. Beyond Accountability for Reasonableness. Bioethics 2008; 22: 101–12; M. B. Mahowald. Why Retreat to Procedural Justice?. The American Journal of Bioethics 2001; 1: 25–26.
\end{itemize}
rationale for compensation because, and only because, it is a means to the social and political objectives of securing people’s opportunities.26 The next subsections examine different problems which this raises for Daniels’ account. The first relates to the role of pain relief in treatment and the second to the rationale for providing pain relief for those who cannot be cured.

Reducing pain in treatment

In the delivery of medical treatment the role of pain relief differs. Sometimes treatment is painful and could thus be supplemented by medicaments or other initiatives to relieve pain. In other cases only some forms of available treatment are painful and pain might be one reason for preferring one treatment over another. It is interesting whether Daniels’ account, with its focus on opportunities, is able to justify taking the relief of pain into account.

To see why we may doubt this, consider first a person for whom the available treatment is painful. If the treatment is able to effectively restore the person’s normal functioning, it is hard to see how an account justifying treatment based on its ability to restore normal functioning can argue that pain relief should be supplied as well (or at least that it should be provided free of charge). Aspirin, Codeine, Ibuprofen, Morphine, and Paracetamol, analgesics included on the WHO Model List of Essential Medicines, would not be provided in any such cases, however bad the pain.27 Or consider a situation where we can choose between two treatments, which are equally effective in restoring opportunities. They differ, however, in how painful they are to undergo. Suppose, for instance, that an invasive procedure has the same quality of outcome as an

alternative non-invasive procedure, with the exception that the former will bring severe post-surgery pain while the latter is painless. Daniels’ account is, in principle, indifferent as to whether that treatment is carried out in a painless or agonizing manner. Since both of these criticisms would surely reflect badly on Daniels’ account, we will discuss three possible answers to them.

The first reply to be considered doubts the relevance of wellbeing in a healthcare context. Briefly considering the idea that wellbeing or welfare is a more plausible rationale than preserving opportunities, Daniels dismisses the idea, writing that ‘much health care affects quality of life in other ways, so the benefit of reducing pain and suffering is not general enough for our purposes’. But this reply addresses the claim that health care is provided solely to ease pain and suffering. However, that is not the present claim, which is rather that pain and suffering are (at the very least) factors among others to be taken into account when assigning healthcare. Furthermore, Daniels states that ‘some suffering, for example, some emotional suffering, though a cause for concern, does not obviously become a concern of justice’ (Daniels 1981, 169). But our claim leaves open the question of whether justice is concerned with all (human) suffering. We merely need to show some cases where pain and suffering are a matter of justice. The amount of avoidable pain the state chooses to inflict when administering medical treatment is very much a matter of justice. Some suffering may not be a matter of justice, but that is not simply because it falls into the category of suffering. Other considerations are needed to support that conclusion. We may think that Daniels’ example of emotional suffering would often not be a matter of justice because it is impermissible for the state to interfere with citizens’ private lives by, for instance, compensating jilted lovers. But the state is not acting outside its jurisdiction when it

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provides less painful rather than more painful treatment. Thus, these answers from Daniels are inadequate to uphold the view that pain and wellbeing are not a concern in these matters.

Another type of answer available to Daniels would be to concede the importance of wellbeing, but claim that his account is compatible with taking pain reduction into account. Let’s examine some possible arguments for such compatibility. The first compatibility claim could be to submit that relieving pain is, in practice, often necessary for doctors in order to perform a given treatment. But this does not provide a reason to prefer the least painful treatment under the stipulation that we are choosing between equally efficient treatments. Furthermore, it is bizarre to say that the only reason doctors should ever prescribe painkillers is to make their job easier, rather than to ease pain itself, so this argument for relieving pain is not satisfactory.

It could also be submitted, drawing on Rawls, that we should prevent pain to secure the ‘social bases of self-respect.’ This, however, also seems inadequate. In some cases persons may receive unnecessarily discomforting treatment from the state without feeling disrespected. Many patients do not have a full understanding of the treatments available for their condition, so they would not know that they had received a more painful than necessary treatment. If, for all they know, the state has done as well as it can for them, why would they feel disrespected? Moreover, even if they do know that there are less painful treatments available, it will probably also be known that the state consistently refuses to accept pain reduction as one of its goals, and is merely acting on its stated principle. Again, in such circumstances patients may well feel greatly discomforted but not disrespected. It could be further countered that in such cases, regardless of patients’ subjective feeling of being respected, an objective state of
disrespect is present. However, it seems highly doubtful that one could draw from Daniels’ work an objective notion of disrespect that arose specifically in cases of avoidable pain given Daniels’ rejection of wellbeing as a measure of justice in healthcare. Thus, the second argument for the compatibility of Rawlsian justice with pain relief also fails.

A final reply to the criticism is suggested by Blinderman. He argues that eliminating pain should be considered a part of protecting opportunities. On this account the issue has so far been discussed from the wrong perspective. Daniels need not argue that wellbeing or relief of pain is unimportant in the context of health care and he need not claim that protecting opportunities is compatible with the different concern of pain relief. Instead protecting opportunities includes providing the relief of pain. To illustrate why this is so Blinderman provides the following example of how this can be:

As patients progress towards death their opportunities become profoundly limited. Nonetheless, we must acknowledge that one goal of palliative care is to preserve this limited opportunity range. Terminally ill patients may hope to communicate meaningfully with loved ones, reflect on their lives and finish a variety of projects. Such opportunities would be incompatible with pain and suffering.

For that reason he argues that Daniels’ account is very able to give us good reason to supply palliative care. He notes, however, one important limitation to that view: situations where we cannot bring people back to normal functioning. As this is

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29 A referee suggested this response.
30 Blinderman, Palliative Care, Public Health and Justice: Setting Priorities in Resource Poor Countries: 107.
31 Ibid.
discussed in the next section, we can set that aside in order to assess whether Blinderman’s argument is plausible in the important context in which he offers it.

The first thing that should be granted to the argument above is that since functioning is age-specific we can reasonably acknowledge that the palliative care in the example can be supplied by Daniels. This is so because it restores functioning in the relevant sense and can thus firmly be justified by the Rawlsian approach to health proposed by Daniels. We will not argue that it is stretching the concept of protecting opportunities. But we do argue that it is far from self-evident from the provided example that Daniels’ account can, in general, recommend palliative care. The reason for this is that in the example palliative care is the very thing restoring functioning and protecting opportunities. Surely, then, it can be incorporated into Daniels’ framework. But what happens when protecting opportunities and relieving pain come apart? Suppose a patient already has the ability to communicate with family and reflect on her life, but also suffers from severe pain. We can provide morphine, which will slightly reduce their overall ability to communicate and reflect, but will significantly reduce the pain. If the patient prefers to receive the morphine, we should surely provide it. But Daniels’ account cannot say this, as the morphine does nothing in terms of restoring opportunity – indeed, it slightly reduces opportunity through reducing the ability to communicate and reflect. The fundamental problem – the tension between the objectives of alleviating pain and protecting opportunities - resurfaces.

Reducing pain - beyond treatment

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Aside from whether Daniels’ account is able to provide palliative care as an integrated part of treatment, another important complication springs from the focus on restoring opportunities. There seem to be cases where the Rawlsian rationale developed by Daniels suggests care should not be provided at all. The thrust of the critique presented here is that if we allocate healthcare solely to restore ‘normal functioning’ in order to protect opportunities, many kinds of important palliative care initiatives should not be undertaken at all as they do not serve this purpose. On the face of it the Rawlsian idea of restoring people to the norm leaves those who cannot be so restored – who, we may hypothesise, are often the most ill – without any medical assistance. Consider Daniels’ statement that ‘if we can minimize the impact of the deficit on opportunities we have an obligation to do so...’. The critique is then straightforwardly to ask what we owe people when we cannot minimize the health impact on opportunities. When we are concerned with health deficits (or deviations from normal functioning) because of their impact on people’s opportunities, why should we then provide care for those whose opportunities we cannot bring back or improve?

There is a fairly obvious response to this second problem. Daniels observes that ‘not all treatments are cures, and some institutions and services are needed to maintain persons in a way that is as close as possible to the idealization’, where idealization refers to normal functioning. Daniels labels such institutions a ‘third layer of institutions’, adding them to the layers aimed at preventing or curing disease. But this response is in clear tension with the objective of restoring normal functioning, as part of

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33 Segall argues that this is also the case where measures outside the traditional health care setting do a better job of protecting opportunities and in cases where people of old age don’t have any life-plans left to pursue: Shlomi Segall. 2010. Health, Luck, and Justice. Princeton, NJ: Princeton: 32–36; 93.
34 A point which Blinderman concedes Blinderman, Palliative Care, Public Health and Justice: Setting Priorities in Resource Poor Countries: 107.
35 Daniels, Just Health: 148.
36 Daniels, Just Health Care: 48.
the activities of this ‘third layer of institutions’ will be to restore minor functionings
which make it no easier to create or pursue life plans. For instance, pain relief may
sometimes be neutral (or worse) regarding cognitive performance. Resources are thus
allocated to activities with little or no influence on people’s opportunities in the
Rawlsian sense.

This problem is exacerbated when we consider what Daniels calls the fourth
layer of institutions, which ‘involves health care and related social services for those
who can in no way be brought closer to the idealization’. This seems to be where
palliative care for those who cannot be cured is located. But here the tension between a
justice-based rationale of restoring or protecting opportunities and the provision of
care for those we cannot help in such a way is apparent. For if a patient is beyond the
point at which we can bring them closer to normal functioning, it is clear that the
objective of restoring normal functioning to protect opportunities cannot provide the
rationale for their treatment. It is, then, very hard to see how Daniels can maintain that ‘all these institutions and services are needed if fair equality of opportunity is to be
guaranteed’. None of the fourth layer activities will enable people to construct and act
upon life plans. Freedom and opportunity in the Rawlsian senses will not in any way be
expanded by the activities undertaken here. It would, as Daniels seems to agree, reflect
badly on the Rawlsian theory of justice in health if such services cannot be provided in
the name of justice. This would in effect leave Daniels’ account without the ability to
justify palliative care.

Stopping short of accepting that people whose opportunities we cannot improve
should not be aided, two possibilities are seemingly open to the Rawlsian. One is to

37 Ibid.
38 Ibid.; Daniels, Just Health: 62.
present other reasons of justice for providing the care under discussion; the other is to point to values outside the scope of distributive justice able to secure the provision of such care. Considering the first possibility, wellbeing or welfare would be suitable candidates for this. But as should be clear from the earlier discussion this amounts to invoking non-Rawlsian reasons, and furthermore, to invoking reasons Daniels elsewhere considers not to be the right reasons for providing care. This approach raises a rather delicate question: if we prefer to go with provisions based on welfare rather than those based on opportunities when they differ in their recommendations, then why not use welfare from the outset? Thus this line of defence from the Rawlsian increases rather than decreases the extent to which we doubt that opportunities are the right focus.

But perhaps Daniels and other Rawlsians need not introduce other justice values and furthermore need not to be embarrassed that their theory cannot justify the provision of palliative care to those whose opportunities we cannot improve. For as Daniels writes, ‘by the time we get to the fourth layer moral virtues other than justice become prominent’, or similarly, that ‘[t]hese services raise serious issues, for example about compassion and beneficence, that go beyond justice’. Although the word is not used, this appears to be a gesture towards charity. But non-restorative treatment cannot be left to the contingencies of charity. Some cases at least are unambiguously matters of justice and Daniels perhaps agrees when he asserts that ‘we owe people health care and related social services even when they cannot be brought closer to idealization’. While Daniels could say that those matters are of no concern to justice,
his hesitation to do so reveals that he does not consider this an attractive solution. We concur.

The strength of the objections examined here and in the previous section, and the importance of the lack of suitable replies in Daniels’ framework can be illustrated by an example where they come together. Consider the case of cancer patients, often associated with palliative care. When the cancer is thought treatable, treatment will be provided in the most efficient way, regardless of how painful that may be. If the cancer turns terminal, any morphine publicly provided for instrumental reasons – to make medical procedures easier to perform – will be switched off, and the patient left in agony, if he cannot afford to pay for continued treatment and no charitable individual or organisation comes forward. Such cases show that, contrary to Daniels’ claim, it is simply not true in the context of the important areas of palliative care that an appropriate extension of Rawlsian theory accommodates egalitarian intuitions. The justificatory structure of Rawlsian justice, either orthodox or extended as Daniels proposes, leaves it indifferent to some kinds of overwhelmingly compelling medical need.

IV. RAWLSIAN ALTERNATIVES

Having considered Daniels’ account and found it unable to justify palliative care in a satisfying manner it might be worthwhile to consider alternative replies which could be used to address this discussion from a broader Rawlsian framework.

The Rawlsian might, firstly, suggest that our claims have failed to account for the extent to which their favoured redistributive theory provides everyone with sufficient goods to secure their basic needs without the need for special provision. In particular, Rawls’ difference principle allocates income and wealth to the greatest benefit of the
least advantage. Under such an egalitarian distribution it could be thought sheer hyperbole to talk of cancer patients without morphine, especially given the fact that Rawlsian justice will compensate persons who do not receive the expected social primary goods owing to illnesses or accidents. Views along similar lines are also expressed by Daniels.

We do not think this response is sound. It is simply not the case that Rawlsian redistribution provides for all the needs that it should. Certain medical treatments that may significantly decrease the amount of pain suffered by a patient may be beyond the means of some such persons even after redistribution. The Rawlsian compensation only provides for the loss of social primary goods, primarily income, and is insensitive to the cost of individual health care needs. The cost of an individual’s palliative care, even in an otherwise egalitarian society, may exceed the income they have lost due to illness. In that case the compensation they receive will be insufficient to meet their health care need. Even where the necessary treatments and aids are within the buying power of those who need them, it is simply unfair that the provision of such things should come out of their share of goods, leaving them with less money to spend on other things. Why, the egalitarian asks, should the ill have less money to spend on food, accommodation and other essential needs just because they are ill and want to be free of pain? In this regard more subjective ‘luck egalitarian’ distributive theories such as equality of resources, equality of opportunity for welfare and equality of access to advantage seem to be preferable, on account of their ability to take into account disadvantaging natural characteristics.

A second Rawlsian response, like the first, aims to provide for palliative care through the difference principle. It differs from the first by adding health care to the list of social primary goods to be distributed by that principle, on the basis that health is something you want, whatever else you want.  

This seems a clear improvement on the standard Rawlsian theory as it provides a principled basis for providing palliative care where it does not further opportunity restoration. Yet it still falls short of what is required. Even if the list of primary goods relevant to justice were lengthened in this way, many of the inegalitarian effects of Rawlsian theory regarding health and healthcare would remain. As Allen Buchanan points out, Rawls proposes that principles are selected from behind a ‘veil of ignorance’ that would ‘preclude a solution to the problem of weighting health care against other primary goods because the answer will depend upon facts about the particular conditions of the society in which the notions in question are to be applied’ (Buchanan 1984: 61). Thus, the theory cannot guarantee any significant level of support for healthcare that does not restore opportunity as the decision regarding the weightings of particular primary goods would be left to politics to decide. This response does at least give palliative care representation within Rawlsian theory, but this may well amount to little in practice.

The final Rawlsian response accepts that on the test of accounting for natural variations Rawlsian justice fails. But rather than adjust the theory, as the second
response suggested, the third response insists that this shows the test to be incompatible with the Rawlsian requirement that theories of justice should be neutral between conceptions of the good. In other words, palliative care is not provided because to do so would prioritize some conceptions of the good (specifically, those that place some value on pain relief) over others.

We have two comments on this response. First, were it true that palliative care was incompatible with the neutrality requirement, that would suggest nothing more than that this requirement is incompatible with egalitarianism. Second, we do not think it is true. Ronald Dworkin’s theory of equality of resources, for instance, acknowledges the neutrality requirement whilst being sensitive to natural variations. Furthermore, we can get further towards equality using primary goods than Rawls and Daniels manage. Allow us to return to the example of terminal cancer patients. The Rawlsian denies them their morphine on two dubious grounds: that absence of pain is not a primary social good, and they are the only things that get distributed; and that they are beyond any recovery to full membership of society. But is the benefit of being free of intense pain really only a conception of the good-relative benefit? Perhaps there are some flagellants who do not view this as a benefit; nonetheless, we feel confident that we could find as many, if not more, persons whose ends are not served by their possessing primary social goods such as wealth and power. We are inclined, then, to believe that absence of pain is at least as conception neutral as Rawls’ social primary goods.

V. CONCLUSION

In relation to the increasingly important topic of palliative care, it must be concluded that the Rawlsian project, as extended by Daniels, does not provide sound answers. Its inability to recommend the less painful treatment and its willingness to leave those who cannot be cured to the contingencies of charity is unacceptable. We believe this implication reflects badly on the enterprise of applying Rawlsian justice to health and health care. Those looking for a normative account of health care that accommodates palliative care should look elsewhere.