



Introduction to the Special Issue on Justice and Health: Different Perspectives in Different Disciplines

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Abstract

This introduction to the special issue on justice and health sketches four common approaches (philosophical reflection, empirical analysis of real-world situations, empirical investigation of lay persons' perceptions of justice, and empirical inquiry on the role of justice arguments in real-world policy making) and four common specific topics addressed in this emerging field (distribution of health or well-being, access to health care, health insurance arrangements, and priority setting). We observe little fruitful collaboration or interaction between researchers working in different approaches and topics. More interdisciplinary contact would yield richer insights into the evolving inquiry on justice and health.

Keywords Health · Justice · Inequality · Access to health care · Health insurance · Priority setting

“Justice and health” is certainly one of the most pressing issues in the contemporary social and political debate. Even in rich countries with well-developed systems of health insurance and/or a high level of government regulation, large inequalities in health and access to health care persist (World Health Organization, 2008; Van Doorslaer & Masseria, 2004). Moreover, the sharp increase in health care expenditures has led to growing social pressure to introduce some kind of rationing in the publicly financed systems (Clement, Harris & Li, 2009), and this rationing may further exacerbate unfair inequalities or inequities. In poor countries where economic inequalities are larger and people have to pay a large fraction of their health care

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expenditures out of their own pocket (Schokkaert & Van de Voorde, 2011), the issue of justice becomes even more pressing.

The definition of what justice requires in health and health care settings is deeply contested (Daniels, 2008; Powers & Faden, 2008; Ruger, 2010; Segall, 2010; Venkatapuram, 2011). It is not easy to distinguish clearly “justice” from “altruism” or “compassion”, but these are different concepts, and the distinction matters. A reference to justice creates stronger entitlements than a reference to “compassion” (Hausman, 2009), and this has implications for the macro-debate about how to organize the health care system and for the micro-relations between health care professionals and patients with their families. People have strong feelings about how they and other people are treated when they are confronted with suffering, pain and death. More than in most other domains of social organization, the treatment of individuals in the context of health is a matter of “respect for human dignity”: people may be severely hurt in their self-respect and shocked by the lack of respect from others if they feel unjustifiably treated. Given this general background, it is no surprise that “justice and health” has been an important topic of research within many academic disciplines.

The interdisciplinary nature of the inquiry on justice and health is well represented by the collection of papers in this and subsequent special issues of *Social Justice Research*. To put these papers in the context of this diverse research field, below we first sketch a range of common approaches used and topics addressed in this emerging field.

Approaches to Examining Justice and Health

In a primitive way, one can distinguish four approaches to examining justice and health that have emerged in the diverse academic disciplines: (1) philosophical reflection, (2) empirical analysis of real-world situations, (3) empirical investigation of lay persons’ perceptions of justice, and (4) empirical inquiry on the role of justice arguments in real-world policy making.

Approach 1: Philosophical Reflection

This approach seeks to answer fundamental questions regarding the meaning of justice in relation to health. Examples of such questions include: should we care about inequality in health or health care and, if so, why (or why not)? How do we define “needs” for health care? There has never been, and will never be, consensus about the exact content of the justice ideal. But the point of the philosophical reflection is not to reach consensus. Rather, its aim is to clarify the different possible interpretations of the concept of justice. Conceptual clarity is a necessary prerequisite for any serious scientific endeavour. Moreover, conceptual clarity is necessary to assist a well-structured and coherent debate on the rights and duties of citizens in the realm of health and health care and therefore is also an essential element in all democratic decision-making processes.

Approach 2: Empirical Analysis of Real-World Situations

While the first approach of philosophical reflection focuses on abstract justice conceptions, this second approach is concerned about making the abstract conceptions operational and useful for the analysis of real-world problems. For example, the abstract conception of justice and health can be operationalized as removing health inequalities that are linked to the socioeconomic background of the individuals. Empirical analysis of justice and health under this operationalization requires: (a) strategies for measuring such socioeconomic inequality in health, (b) applications of these measurement strategies to the existing situation (e.g., how large is socioeconomic inequality in health in a given society at a given point in time? What are the underlying causes of this inequality?), and (c) reliable insights into the effects of various policy options (e.g., which policy options are most effective to reduce socioeconomic inequality in health?). Comparison of empirical analysis results derived from different conceptions of justice is not only relevant for policy makers. Sometimes, the implications of different justice conceptions are only well understood when one is aware of the policies they support.

Approach 3: Empirical Investigation of Lay Persons' Perceptions of Justice

The third approach focuses on lay person's perceptions of justice. Actual opinions of people in society are likely to be driven more strongly by specific policy proposals than by abstract justice conceptions. Examples of questions using the third approach include: How do people think about justice? How do we understand their reactions on specific policy proposals? It is possible that there is a deep gulf between the coherent conceptions worked out by philosophers and the real-world perceptions of less sophisticated citizens. It is the latter that are most relevant to understand the actual working of society because philosophical theories can hardly explain behaviour. The focus on actual behaviour prompts further questions. How do perceptions of justice link to other values and motivations, such as fraternity or compassion, and are they related to pure self-interest, and, if so, how? When are references to justice just a trick to hide pure self-interested considerations? How are distinctions between justice, compassion and self-interest that matter in a normative analysis also relevant to the explanation of behaviour?

Approach 4: Empirical Inquiry on the Role of Justice Arguments in Real-World Policy Making

While the third approach examines perceptions of justice at the individual level, the fourth approach does so at the level of political decision-making. Whereas the second approach allows us to suggest which policy options should be taken to realize a given conception of justice, only with the fourth approach can we understand if, and if so, how, such reasoned suggestions play a role in the actual

decision-making process. To explain the wide variety in health insurance arrangements in different countries, for example, many factors are likely at play beyond normative theories. Does this variation reflect cultural differences, including differences in perceptions of justice? How do conceptions of justice interact with other social values and economic constraints in the real world? How are the attitudes towards justice at the individual level, as analysed in the third approach above, filtered through the political system? And, how does a specific design of the political system influence the outcomes of the political decision process? All these questions are relevant on their own. But there are also obvious feedback loops. Surely, the political system influences social relations and the adoption of different concepts of justice by the citizens. Without properly taking into account the specific features of the political institutions, a coherent normative analysis may naïvely yield unpredicted and undesirable consequences.

Specific Topics in Justice and Health

Using the aforementioned approaches, researchers have examined a wide range of specific topics of justice and health. These topics include: (A) distribution of health or well-being; (B) access to health care; (C) health insurance arrangements; and (D) priority setting.

Topic A: Distribution of Health or Well-Being

This topic area starts with the observation that health, however measured, is distributed unequally in society, regardless of the inequality measure used. The central question in this topic area is how health inequality relates to justice, which, in turn, prompts two further questions: (1) how do health and well-being relate to each other when considering justice? and (2) is there ethically permissible health inequality, and if so, what is it? One possible position regarding the first question is that the distribution of health is only a partial indicator of ethically illegitimate inequality, and what matters is the distribution of well-being (Hausman, 2007). How important, then, is health for overall well-being? Should we consider trade-offs between health and other dimensions of life, or is this a kind of trade-offs with which human beings do not want to be confronted, and perhaps should not be confronted? Regarding the second question, there are two possible arguments for ethically permissible health inequalities: biology and individual responsibility. Many people argue that health differences due to biological factors (e.g., young versus old, female versus male) are perhaps unfortunate, but not unjust (Daniels, 1988; Norheim and Asada, 2009). The underlying reasoning is that justice is necessarily linked to social organization and that society cannot remove biological differences. Yet, this assumes that it is possible to separate clearly “biological” from “social” influences. This is doubtful, because, for example, a society can decide how much to spend on health care for the old, and providing glasses to people with vision problems can be a cheap and efficient means to tackle biologically determined problems of vision. Another argument

for ethically permissible health inequality refers to individual responsibility, linked to differences in lifestyle. If one accepts that lifestyle choices are indeed free choices and under control of the individuals, the resulting health differences should perhaps not be seen as unjust. Yet, does freedom of choice really exist? This issue of responsibility (or not) for lifestyles is certainly one of the most heavily debated topics in the context of health inequalities (Fleurbaey & Schokkaert, 2012).

Topic B: Access to Health Care

This topic area starts with a seemingly simple premise that in a just society people with the same needs should have the same access to health care. Further reflection, however, raises many difficult questions. To begin, how should we define health care needs? As health status, the capacity to benefit, or the amount of resources needed to exhaust this capacity to benefit (Culyer & Wagstaff, 1993)? In addition, the issue of responsibility pops up again: if patients deliberately choose to forgo care, “equal access” does not at all lead to “equal care”. Is this ethically desirable as patients get the opportunity to follow their own preferences in full freedom, or should at least some patients be protected because their choices are based on imperfect information? Moreover, while a large part of the empirical literature indeed focuses on the potential of treatments to cure diseases, such “effectiveness” argumentation only partially determines attitudes towards equal treatment. When suffering and in pain, human beings want to be treated with dignity and respect. They want to be listened to and to get reliable information, transmitted in a respectful way. Health care is not only about health.

Topic C: Health insurance Arrangements

Inequality in health care is strongly influenced by the organization of the health care system, and health insurance arrangements is one of the well-studied topic areas (Cutler & Zeckhauser, 2000). In some (mainly poorer) countries, there is hardly any insurance available and patients have to pay their health care expenses out of their own pocket. With an unequal income distribution, this leads necessarily to unequal access to care. In extreme cases individuals have the “choice” between on the one hand foregoing health care and remaining ill and on the other hand buying health care but ending in dire poverty (Wagstaff et al. 2018). In countries dominated by private insurance, coverage can be broad or narrow and on an unregulated insurance market, high and low risks will have to pay different premiums. In fact, actuaries call this situation in which premiums are based on expected costs “actuarially fair” (Arrow 1963). Most citizens and ethical observers will see this as a misnomer, however. They feel that such market outcome is grossly unfair, because people cannot be held responsible for many of the factors making them high or low risks, such as genetic endowments. Yet another model can be found in most high-income countries, where there is a high level of government regulation in a setting with either social insurance or tax financing of health care expenditures. Health care is provided nearly freely at the point of service. One of the “costs” of this choice is the severe

restriction of citizens' freedom of choice. Most real-world health care systems are characterized by a hybrid mixture of these different components (out-of-pocket financing, market forces, and government regulation). Whatever the mixture may be, the way a health care and health insurance system is organized reflects differences in the conception of what a just society is and what the role of government intervention should be in a just society and has direct implications for how just the distribution of health outcomes is.

Topic 4: Priority Setting

Priority setting or, negatively formulated, as rationing, refers to decisions regarding which treatments are included in the insurance coverage and which treatments are not. These decisions have to be made in all insurance systems and are especially difficult in publicly financed government systems. The dominating technique for making these decisions is cost-effectiveness analysis, aiming at “producing” the best possible quality (the largest number of quality-adjusted life years) with a given government budget (Drummond, Sculpher, Claxton, Stoddart & Torrance, 2015). This traditional technique is more focused on efficiency than justice. However, this is precisely why it raises difficult justice issues. If individual patients can buy non-reimbursed treatments out of their own pocket, unequal access to health care will result. In a less extreme form, the same is true if treatments are only partially reimbursed with patients forced to pay large copayments. A specific challenge is raised by rare diseases. Reimbursement of the so-called orphan drugs—drugs for rare diseases—is seldom cost-effective, and, in fact, without government subsidies, research in the development of these drugs is usually not profitable. Yet, from an ethical point of view, it is difficult to defend that individuals with rare genetic defects should not be treated just because they are few.

Diverse Inquiry, Disciplinary Orientation, and Need for Interdisciplinary Collaboration

The four approaches and the four topics sketched out above create 16 combinations, represented by 16 boxes in the table below. One can find academic literature in each of these boxes, although some boxes are more filled than others.

Approach	Topic			
	(A) Distribution of health or well-being	(B) Access to health care	(C) Health insurance arrangements	(D) Priority setting
(1) Philosophical reflection				
(2) Empirical analysis of real-world situations				
(3) Empirical investigation of lay persons' perceptions of justice				

Approach	Topic			
	(A) Distribution of health or well-being	(B) Access to health care	(C) Health insurance arrangements	(D) Priority setting
(4) Empirical inquiry on the role of justice arguments in real-world policy making				

There are some links between these different boxes and the traditions of the different academic disciplines. These links are far from perfect but useful to highlight the diverse disciplines that form common clustering of approaches used and topics examined in the inquiry on justice and health. Philosophers focus on the approach (1), covering all four topics (A), (B), (C), and (D) (e.g., Brock, 2009; Daniels, 1985, 2008; Segall, 2010; Wikler & Brock, 2008). There are also philosophers who believe that the approach (3), empirical research on the attitudes and feelings towards justice, is a useful input into the philosophical debate (e.g., Miller, 1992). Psychologists use the approach (3), with a stronger focus on micro-relations in the topics (A) and (B) than macro-issues, such as those represented by the topics (C) and (D) (e.g., Harper, King & Young, 2013; Lundell, Niederdeppe & Clarke, 2013; Niederdeppe, Shapiro & Porticella, 2011). Sociologists also prefer a positive approach (3) to a normative approach (1), but for them the macro-issues represented by topics (C) and (D) are more central than the micro-issues represented by topics (A) and (B) (e.g., Rigby, Soss, Booske, Rohan & Roberts, 2009; Webster, 2004). Together with political scientists, sociologists also analyse actual policy making processes in different societies by the approach (4) (e.g., Abelson et al. 2007; Giacomini, Hurley, Gold, Smith & Abelson, 2004). Public health researchers mainly use the approach (2) to investigate all four topics (e.g., Braveman, 2006; Cook et al. 2014; Hines et al. 2011; Mitton, Smith, Peacock, Evoy & Abelson, 2009; World Health Organization, 2014) and often need a position derived from the approach (1). Economists are active in all boxes of the table although less so in the approach (3) (e.g., O'Donnell, van Doorslaer, Wagstaff & Lindelow, 2007; Cookson et al. 2018; Fleurbaey & Schokkaert, 2012). A notable within-discipline clustering is among normatively oriented economists, social choice and welfare economists, focusing on the approaches (1) and (2), versus among the economists looking at the real-world performance of governments, public choice economists, using the approach (4). This within-discipline clustering is stark and often puzzling to someone outside economics, for example, it is difficult to understand why the research area of the former is called “*social choice theory*” and that of the latter “*public choice theory*”.

It is striking how little fruitful collaboration or interaction there has been between researchers working in different boxes. Researchers from different disciplines rarely communicate even if they work on the same topic using the same approach. A good example is the empirical analysis of socioeconomic differences in health or health care (boxes 2A and 2B) by public health researchers and economists. Despite addressing the same topic, they use very different methods, with public health researchers using a regression model (e.g., Banks, Marmot, Oldfield & Smith, 2006; Cook, McGuire & Zuvekas, 2008) and economists using concentration

curves (e.g., O'Donnell, van Doorslaer, Wagstaff & Lindelow, 2007). In fact, to public health researchers, health inequalities always mean differences across population groups (e.g., income or racial groups) (Braveman & Gruskin, 2003; Duran & Pérez-Stable, 2019), but within the economic or philosophical analysis, this group level is less relevant (Asada, 2013; Fleurbay & Schokkaert, 2009). Furthermore, interaction between researchers active in different boxes is even more rare even if these researchers are from the same discipline.

The silo of boxes is a missed opportunity for the evolving field of justice and health as more interdisciplinary contact would lead to richer insights. Here we offer three examples to support for cross-fertilizations. First, social norms, dominating values and social networks have a strong influence on opinions and attitudes, and prevailing attitudes in society, in turn, limit the potential of policy actions to change the existing situation. Rows (2), (3) and (4) are therefore closely linked. Second, the empirical analysis of the actual situations and possible policy options (row 2) requires concepts of justice. Value judgments underlying empirical analysis are often implicit, but the conceptual insights derived from the philosophical reflection (row 1) will make them explicit and transparent. Finally, the topic of priority setting is much more than simple cost-effectiveness analysis. One can explore a deeper philosophical reflection on the criteria that should be used for rationing (1D) (Daniels & Sabin, 2002; Dworkin, 2000), examine the consequences of specific decisions (2D), incorporate the attitudes of citizens through surveys or citizen's panels, and devise decision-making procedures that are acceptable for the population at large (4D).

An important obstacle to greater interdisciplinary communication is the lack of a common terminology. In some cases, the same term is used with very different connotations. We have already given the example that actuaries define a situation in which insurance premiums perfectly reflect expected expenditures as “actuarially fair” although almost none of the other disciplines would accept the resulting premium differentiation as fair. Another example is the term “utilitarianism”. For philosophers and welfare economists, it refers to the specific social objective of the simple greatest sum of the utilities of all individuals in society. In this (original) interpretation, in some cases utilitarianism can advocate a large degree of redistribution of resources. Outside philosophy and welfare economics, however, the term “utilitarianism” is used more loosely. In some cases, it broadly denotes *all* consequentialist objectives, in which policies and behaviour are evaluated on the basis of their consequences rather than on intentions or deontological considerations. It is sometimes even used to indicate a system of values that gives a great weight to effectiveness or, even more loosely, to “market” or monetary outcomes. We are then really far removed from the original philosophical concept.

There is then more than just a confusion of terminology. Researchers from different disciplines may also have diverging convictions about what the focus *should be* when examining health and justice and, worse, they may be tempted to evaluate the contributions of other disciplines from their own disciplinary perspective. For example, if one evaluates the philosophical work on the basis of what it contributes to the understanding of actual behaviour, one may conclude that it is nearly useless. But, if one is convinced that the final goal of the academic research is to define a conceptually coherent view on justice, the profusion of conflicting empirical findings may

just create a feeling of intellectual disorientation (Deutsch, 1983). Another example is among empirical analysts. If one is convinced that abstract modelling is necessary to structure the complicated reality, one may become very irritated by empiristic interpretations of data that seem to be collected in an ad hoc way. But, if one deeply distrusts formal modelling, one may start making jokes about the simplifying assumptions that are needed to construct a formal model. And, of course, narrow-minded focus on one's own restricted perspective is strongly enhanced by a sheer lack of knowledge of the contributions made by other disciplines.

Collection of Papers in this Special Issue

In this and subsequent special issues on “Justice and Health”, we have deliberately aimed at bringing together good contributions from different disciplines, positive and normative, qualitative and quantitative, model-driven and more inductive. The different papers in this collection are arranged in the table below, with some of them in multiple boxes, indicating the beginning of much needed interdisciplinary interaction.

Approach	Topic			
	(A) Distribution of health or well-being	(B) Access to health care	(C) Health insurance arrangements	(D) Priority setting
(1) Philosophical reflection	<i>Hausman</i>		<i>Hausman</i>	<i>Hausman</i> <i>Luyten/Denier</i>
(2) Empirical analysis of real-world situations	<i>LoPalo et al.</i>	<i>Negrin-Hernandez et al.</i> <i>Rais/Tubeuf</i>	<i>Rais/Tubeuf</i>	
(3) Empirical investigation of lay persons' perceptions of justice	<i>Drolet/Drolet</i> <i>Costa-Font/Cowell</i>	<i>Drolet/Drolet</i>	<i>Maldonado et al.</i>	<i>Luyten et al.</i> <i>Costa-Font/Cowell</i>
(4) Empirical inquiry on the role of justice arguments in real-world policy making		<i>Smith et al.</i>	<i>Smith et al.</i> <i>Maldonado et al.</i>	<i>Charlton/Rid</i> <i>Luyten/Denier</i>

Hausman is the only really philosophical paper. In his general approach, he discusses the question of why we should be interested in the distribution of health as such, and he argues that health inequality is only relevant because of the correlation between health and other dimensions of life. He applies this insight to make interesting suggestions about how to organize the health insurance system and the ethical foundations of priority setting. This latter topic is also discussed by *Luyten and Denier*. They present a broad overview of different ethical and psychological arguments concerning priority setting, finally drawing the conclusion

that decision-makers should not fall into the trap of formulating simplistic decision criteria.

Values and attitudes that play a role in priority setting are also discussed in three other papers, and they offer very different perspectives. *Costa-Font and Cowell* argue that the essentially normative concept of inequality aversion plays a critical role in issues of justice in health and discuss whether inequality aversion has the same content in the health and income settings. They also give an overview on the empirical work attempting to measure the concept. Their paper is an illustration of a typical economic approach, aiming at deriving reasonable values for abstract normative concepts. *Luyten et al.* take a very different approach, empirically assessing influences of personal disposition—optimism and pessimism—on priority setting preferences of individuals. Finally, *Charlton and Rid* go beyond individual values and preferences to analyse the real political decision-making process within the National Institute for Health and Care Excellence (NICE), focusing on the treatment of innovative drugs.

There will be six more articles in the next volume of this special issue. Three of them look at the empirical reality of the distribution of health and health care. *LoPalo et al.* describe the situation in India, as an example of a situation where social inequalities (in their case caste hierarchies) are not only bad for the health of individuals but also for the health of the entire population, through the relative prevalence of open defecation. *Negrin-Hernandez et al.* focus on the more specific issue of specialist health care access in Spain, exploring a possibility of the concurrent use of public and private insurance as a sign of patients' strategic behaviour, which could be a source of inequity. *Rais and Tubeuf* analyse the distribution of R&D expenditures for the treatment of rare diseases.

The other papers offer different perspectives on the attitudes towards health and health care and the interaction with social structures. *Drolet and Drolet* focus on the micro-level and analyse the psychological mechanisms underlying the increase of the popularity of labiaplasty, an invasive surgical procedure reducing the size of the labia minora. *Maldonado et al.* take a macro-perspective and use survey data to test the hypothesis that people's valuations of universal health care are associated with risk exposure and humanitarian attitudes across different institutional contexts. Finally, *Smith et al.* discuss the role of justice in the practice of public health policy making. Their qualitative interviews reveal that this role is perceived differently by policy makers working in the domain of chronic disease prevention, who see justice as "part and parcel" of their work, and policy makers in the domain of public health emergency preparedness, who see it as a "constraint" on their basic aims.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no competing interests.

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