The Evolving Idea of Social Responsibility in Bioethics

A Welcome Trend

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Abstract: This article discusses the notion of social responsibility for personal health and well-being in bioethics. Although social responsibility is an intrinsic aspect of bioethics, and its role is increasingly recognized in certain areas, it can still be claimed that bioethics in general is committed to an individualistic theoretical framework that disregards the social context in which decisions, health, and well-being are situated. The philosophical premises of this framework regard individuals as rational decisionmakers who can be held accountable for their health conditions and who should be the primary objects of intervention in attempts to reduce lifestyle-associated chronic diseases. There are, however, social determinants of health that challenge this conclusion. Because their impact can be controlled, to a certain extent, by social and public policy decisions, their existence shows the inadequacy of the purely individualistic approach. I suggest, accordingly, that bioethics would benefit, both academically and societally, from a more social perspective. Bioethical studies that acknowledge, from the start, the social determinants of health would be more amenable to constructive multi- and interdisciplinarity, and a more balanced account of responsibility would further the contribution of sound bioethical work to sensible public policies.

Keywords: bioethics; social responsibility; individual responsibility; social determinants of health

Introduction

Who is responsible for the health of individuals? In recent discussions on "self-inflicted" ailments, the role of individuals themselves has been emphasized. Public debates and policy documents have singled out adverse health conditions that are allegedly caused by lifestyle choices, and many academics have argued that such conditions should form a special case when it comes to our shared duty to provide treatments to illnesses and diseases.[1]

The responsibility of individuals for their own health has been discussed especially in the context of distributing healthcare resources in the affluent West. The World Health Organization (WHO) has estimated that at least a third of the disease burden in high-income countries is attributable to the use of tobacco and alcohol, high blood pressure, unhealthy cholesterol levels, and obesity.[2] Because this part of the burden could most probably be alleviated by decisions made by individuals, it has been argued that making the right decisions is everyone's moral responsibility. The allocation of scarce resources to the treatment of conditions that could have been prevented by the choices of individuals has, accordingly, been seen as a challenge to the just arrangement of healthcare services in affluent countries.[3]

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Holding individuals responsible for their health-related choices is not, however, as straightforwardly correct as thought by the proponents of the individualistic view. The health of individuals, apart from their own decisions, is also determined by cultural, societal, and socioeconomic factors that are beyond their control;[4] and it is possible to counteract the health impact of these factors by legislative and policy decisions.[5]

In this article, I review the role and evolution of the concept of social responsibility in bioethics. By this I mean a wide notion of responsibility that takes into account the social determinants of health, their impact on the health of individuals, and the responsibilities of legislators, social-policy makers, and society as a whole for controlling them. I begin by introducing the rival view that holds individuals responsible for their own health. I then go on to examine its role in bioethics, the role of more social views within the discipline, and the possibility of introducing a more widely social concept of responsibility into bioethical considerations. It has been argued that bioethics, unlike its neighboring disciplines in the social sciences, by and large relies on an individualistic, as opposed to a social, view of responsibility for health and well-being.[6] The idea of social responsibility has been a part of bioethical discussion from the beginning, but the focus on individualistic medical ethics has been claimed to result in a lack of a consistent social theory of health. In conclusion, I urge bioethicists to take the social determinants of health as the starting point of their studies, not as a side question. This would help make bioethics a constructive discipline both academically and societally.

Claiming Individual Responsibility for Health

The Responsibilization of the Individual

The growing scarcity of resources in the health sector has led to suggestions that we combat this by shifting the burden of responsibility toward the individual. As a part of this, problems like unemployment and poverty have been desocialized,[7] and a growing trend of "responsibilization" has followed. In this trend, people are seen as "expert patients" and consumers who manage their own lifestyles and exercise choices to promote—or not promote—their own health and well-being.[8] This framework allows us to hold individuals accountable for their own health.

Numerous studies give insight into how and when the change of mood took place. For instance, in the UK, whereas earlier policy documents (from around 1999) emphasized social and material factors such as social exclusion and inadequate housing, the more recent ones (2003 onward) place a much greater emphasis on individual choice and call for individual responsibility for health. Interventions to tackle health inequalities are increasingly aimed at changing the behavior of people "at risk."[9] A study conducted in the Netherlands reports similar findings. It suggests that there is a relation between introducing market mechanisms to European healthcare systems and the promotion of individual responsibility. By considering patients as consumers, the health sector is relieved of some of its responsibilities. In European healthcare, there is a move away from collective funding and control toward increased individual responsibility.[10]

Recent evidence suggests that, also among the general public, there is at least some willingness to hold individuals responsible for their "self-inflicted" ailments.

There is support, for instance, for giving lower priority when allocating organ transplants to patients who can be seen responsible for causing their organ failure, for holding individuals responsible for adverse health effects caused by smoking, and for taking many other lifestyle habits into consideration in healthcare decisions. Public willingness to pay the costs associated with health problems is lower if the problems are related to private health behavior.[11] The responsibilization of individuals has also been found to result in a stigmatization in the media of individuals with chronic disease linked with "bad behavior."[12] Healthcare professionals have also been reported to have attitudes that can endanger healthcare provision. For instance, obese individuals may hesitate to undergo necessary examination and screening procedures for fear of being stigmatized.[13]

Theoretical Accounts

The justifications behind the arguments for assigning responsibility for health to individuals are mainly deontological or utilitarian. The deontological approach draws from the assumption that individual responsibility for health is a matter of fairness between taxpayers and welfare claimants. As there is evidence to suggest that there is a relation between chronic disease and lifestyle, individuals should, it is claimed, be held accountable for their lifestyle as a prerequisite for receiving public resources.[14] Utilitarian arguments emphasize either the assumed beneficial effects of taking responsibility for one's own lifestyle or the predicted negative effects of taking away individual responsibility, which could undermine the individual's own incentive to take care of herself.[15]

Most of the current theoretical arguments offered in support of increasing individual responsibility for health are found within the responsibility-sensitive egalitarian tradition.[16] In this tradition, while healthcare is recognized as a right, the normative distinction between chance and choice is highlighted. The basic tenet is that inequalities that derive from unchosen features in people's circumstances are unjust, whereas inequalities that result from the choices people make voluntarily are just. Responsibility depends on a person's ability to make decisions and to control her life, and possessing control means that any adverse consequences that follow can be traced back to the person in control. Conversely, the absence of feasible alternatives and lack of control can lessen responsibility. The obviously difficult distinction between voluntary choice and circumstance (chance) is at the center of the original debate.[17]

Recent proposals drawing on responsibility-sensitive egalitarianism for increasing the role of individual responsibility within healthcare suggest a limited but significant role for individual responsibility in the rationing of healthcare resources.[18] Practical suggestions have included a forward-looking take on responsibility in which patients suffering from a chronic lifestyle disease should sign a contract in which they commit to frequent medical follow-ups or otherwise risk getting lower-priority service in healthcare.[19] Another idea has been the implementation of a bonus-malus system, which would use an algorithm to decide which interventions will be included in the basic benefits package system, with personal factors such as smoking behavior considered as a part of the algorithm.[20]

Bioethics and Individualism

It has been suggested that bioethics as a discipline does not adequately take into account the social view of responsibility for health and well-being but focuses, instead, on individual matters such as personal autonomy. Furthermore, it has been claimed that this neglect enforces exaggerated conceptions of individual responsibility.

The lack of consideration for social responsibility is clearly visible in the individualistic perspective of the majority of mainstream bioethics.[21] Academics in the field address ethical questions, including those with obvious social dimensions, exclusively or at least predominantly in terms of individual autonomy, consent, and personal rights. The issues tackled include the control of human genetics, the use of humans in scientific experiments, and the exploitation or empowerment of the vulnerable. Individual rights and autonomy are obviously important considerations in such matters, but critical authors have argued that they do not tell the whole story. For instance, genetic technologies can be tackled from the viewpoint of individual rights. But this choice of approach can encourage ethicists to ignore comparative questions like, Could a nontechnological or low-tech solution do more good to population health than a high-tech one? Material investments in high-tech medicine are sometimes made at the expense of promoting community health frameworks that could offer far greater benefits for all.[22]

According to Albert R. Jonsen, bioethics lacks a social theory. Jonsen maintains that most bioethicists have a tendency to consider individuals as rational and impartial decisionmakers, and to ignore the social context of human decisions and actions. Staying in its "familiar territory of personal autonomy and interpersonal beneficence and non-malficence [*sic*],"[23] bioethics considers justice only as a background question. According to Jonsen, bioethics, from its beginning, bought into the moral framework of clinical medicine, was dedicated to the treatment of individuals, and left out the broad social and cultural context within which medicine and individuals exist.

Individualistic bioethics and the political shift toward the responsibilization of the individual are based on similar assumptions, as the conditions of autonomy and the requirements holding people accountable for their condition are essentially the same. People are discrete, rational decisionmakers who are, as long as they are competent and can choose their ways freely and without explicit coercion, in charge of their own well-being. The social context in which the decisions are made is of less consequence.

The background idea that explains this connection is the biomedical model of health shared by individualistic bioethics and politics that assigns personal responsibilities for health.[24] In the biomedical, disease-centered model, health is defined primarily as the absence of disease. Furthermore, many chronic illnesses are associated with known and controllable risk factors such as cigarette smoking, a bad diet, and heavy drinking. This being the case, risk factors can be controlled best by aiming interventions at individuals.[25] According to Jacquineau Azétsop and Stuart Rennie, such "medical individualism" assumes that individuals voluntarily choose health behaviors in relative isolation from their social surroundings. Consequently, poor health is seen to follow from exposures to health risks that the individual decided not to avoid.[26]

The disease-centered medical model of health enables individualistic studies in bioethics and fosters an emphasis on individual control over health in politics.

The problem with the model and the ensuing academic and policy activities, however, is that they fail to account for the correlation of economic and social inequalities with health issues locally and globally—that is, why some persons are more "at risk" than others in the first place.[27] The medical model of health may prevent people from seeing socioeconomic inequality as a source of poor population health.[28] It may also cause untoward medicalization, dismissing environmental and social solutions and promoting high-tech medical ones.[29] Responsibility for health is placed on the individual, and health problems are seen as something to be addressed only by biomedical means and by behavior changes. Autonomy-focused bioethics allied with the medical model of health is theoretically incapable of taking non-pathological causes of ill health properly into account.[30]

Bioethics and Social Responsibility

The Implicit Position on Social Responsibility in Bioethics

Bioethics is not only about individualism. According to Peter J. Whitehouse,[31] in the very beginning bioethics was concerned with large ecological and societal issues, but this dimension has since been overshadowed by more individual-oriented endeavors. According to Jonsen, the emphasis on personal autonomy and the de-emphasis on social questions can be partly explained by the urgency of individual-related ethical questions. For example, the threat of eugenics, brought about by the emerging possibilities of genetic testing, screening, and manipulation, created an immediate need to stress individual rights and consent. Similarly, scientific experiments exploiting individuals, such as the Tuskegee Syphilis Study, forced the issue of consent to the center of the debates. And according to Jonsen, the approach of personal autonomy became even more dominant in the wake of the debates on life-sustaining treatments in 1970s.[32]

Although Jonsen critically observes the dominance of individualism in bioethics, he does not claim that there has been no room for social responsibility. He asserts that social responsibility is often present in bioethical deliberations and that many bioethicists are strongly committed to it. But he claims that, as a discipline, bioethics treats social responsibility as a side issue and does not give it due consideration. What Jonsen argues is that *as a discipline* and *as a discourse* whose job it would be to educate people to discuss and debate ethical issues, bioethics has yet to integrate the principle of social responsibility into its teaching and language.[33]

The multitude of contributions by the proponents of biomedical enhancements provides an example of this. In their rhetoric, new technology is seen as an essential means to making better people[34] and to improving humanity. Although the advocates of biomedical enhancements[35] do not maintain that no other determinants contribute to human well-being, the literature gives a dominant role to genetic and other biomedical advances. These contributions are particularly open to the charge of excessive individualism. They focus almost exclusively on individuals, their choices, and their characteristics and ignore the complex environmental and social background questions. Although the social determinants of health and well-being are occasionally touched on, they, alongside social responsibility, are left in the margins. This means that the ensuing bioethical considerations are founded, at least implicitly, on an incomplete and invalid social theory of health. Bioethicists would do well to find a better balance between the individualistic and the social frameworks.

The Evolution of Social Responsibility in Bioethics

Even if social responsibility is not at the forefront of bioethics, there have been attempts to develop theoretical models that would include the ideas of social responsibility for health and well-being. The discussions on access to healthcare in the 1980s brought social and political philosophy into bioethics,[36] and the growing field of public health ethics starts, by definition, at the social level. More recently, many authors have called for a "bioethics of population health" that would tackle the questions of global and domestic health inequalities, and social justice.[37] They believe that bioethics should abandon its fixation with the clinical dilemmas of high-tech questions and should consider the new technologies only as one determinant of health among others.[38] They further hold that questions of social structure, socioeconomic position, and cultural background should be integrated into moral analyses[39] and demand an organizational change that would promote population health.[40]

Moreover, social responsibility for health is the explicit focal point of the UNESCO International Bioethics Committee's most recent report, On Social Responsibility and Health (2010).[41] The report states that, following UNESCO's Universal Declaration on Bioethics and Human Rights (2005), which devotes an entire article to social responsibility and health, there is a need for new perspectives that go beyond mere medical ethics and bioethics. Scientific progress must be relocated within a context that is open to the political and social world. Thus, there is a strong demand for a broader notion of social responsibility to be used in bioethics, and this is also becoming increasingly visible in the literature.

Norman Daniels provides a comprehensive view on social responsibility for health. He draws on a number of theories of justice claiming that society has an obligation to protect the opportunities of its members. Daniels argues that health is of special moral importance, because maintaining it makes a significant, if limited, contribution to protecting the range of exercisable opportunities open to individuals. Consequently, he argues for a social obligation to protect the health of the population.[42] Daniels discusses the effects that, for instance, education, housing and living conditions, nutrition, pollution, jobs, income, wealth, opportunities, discrimination, and political participation have on health. Daniels' central claims are that these social determinants of health are very unequally distributed among subgroups that differ, among other things, by ethnicity, gender, and class, and that all these factors can be shaped by social policy decisions.[43] It is also likely that public health measures based on the idea of individual responsibility place the heaviest burden on the most vulnerable groups in the population, as those in more advantaged positions are better equipped to pay for the treatments needed. As Daniels maintains, it is questionable to set for the most vulnerable groups a standard of health-promoting behavior that is not required of more affluent citizens.[44] A greater emphasis on social responsibility for health would counteract the original inequalities.

There is an abundance of empirical evidence to support the significance of social determinants. Family wealth, social status, networks, and cultural knowledge of societal processes mold a child's personality and her future prospects. For example, children of educated parents are more likely to receive higher education, and achieving higher education has a tendency to increase awareness of health issues and the ability to control one's life. Poverty in childhood strongly predicts unhealthy habits

as an adult.[45] Recent studies on epigenetics have broadened the scope of the influence that environmental factors have on our health and well-being.[46] The health and well-being of a person are a complex joint effect of interconnected mechanisms involving genetics, epigenetics, social structures, and individual choices. As to the last one, however, as Daniel Wikler notes, actions only rarely have all the attributes that are required for complete personal responsibility—that is, they are seldom fully informed, voluntary, uncoerced, and deliberated.[47]

Holding individuals solely responsible for their own health is not a fair conclusion, because so many determinants of health are beyond the individual's control. Many of these can be strengthened or counteracted by social and public policy decisions.[48]

Toward a Socially Responsible Bioethics

The social determinants of health, which we know exist, can be accounted for in two ways. First, bioethicists whose studies center on individual-related ethical questions can argue that if poverty, lack of education, status, or any other social factor prevents individuals from making autonomous decisions, these should be taken fully into account. Choices that, due to external causes, are not adequately informed, voluntary, uncoerced, and deliberated do not create the personal responsibilities for one's health condition that responsibility-sensitive egalitarianism assigns to people who have autonomously chosen their health-related behavior. Second, bioethicists who want to stress the outcome of policy decisions, whether in terms of justice or in terms of material well-being, can say that the first view is insufficient. If, after a series of autonomous decisions, some individuals and groups are in a worse health state than others, the situation should still be remedied. Whatever the contribution of human decisions, people's health needs ought to be met.

Both ways can lead to the same conclusion. Because people's choices are seldom genuinely autonomous, and because we have no way of knowing in specific cases the quality of their choices during the course of an individual's life, not even the individualistic approach can support the idea of universal personal responsibility for one's health. And the other school does not even endeavor to do this. Why, then, emphasize the importance of the more social method? The answer lies in the practice of autonomy-based bioethics. When the essential answers for increasing health and well-being are thought to lie in biomedical means that the autonomous agent chooses, the primary normative results are always of the following form: if the requirements of individual autonomy, rights, or beneficence are satisfied, we should do *this* and *this*. No matter how many suggestions on alternative perspectives are added after this, all other conclusions are automatically secondary and seem to merit lesser attention. But due to social factors contributing to our health and well-being, we should pay much more attention to these "secondary" considerations. This is the only way to make bioethical studies and their results more realistic.

The recognition of social matters is also necessary because of the multi- and interdisciplinary nature of bioethics. Philosophers cannot see the whole picture unless they can understand and accommodate the presuppositions assumed and results produced by social scientists and other academics from neighboring fields. With this understanding, bioethicists can take on the task of addressing complex social matters on both domestic and global scales.

The recommendations of this new brand of bioethicists would require political and economic decisionmakers to abandon the discourse of individual responsibility for health and to assume, instead, a more social attitude toward solving problems that are, to a large extent, created by social phenomena. This would contribute to a more balanced account of responsibilizing individuals and to responsibilizing, instead, politicians, legislators, economic decisionmakers, and social-policy makers.

Notes

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3. See note 1, Feiring 2008.
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5. See note 4, Daniels 2008; Wilkinson RG, Marmot MG. *Social Determinants of Health: The Solid Facts*. Copenhagen: WHO Regional Office for Europe; 2003.
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15. See note 14, Brown 2005.
16. The original systematic formulation of a responsibility-sensitive egalitarian position was formulated by Ronald Dworkin (Dworkin R. What is equality? Part 2: Equality of resources. *Philosophy and Public Affairs* 1981;10:283–345); further developed by, e.g., Richard Arneson (Arneson R. Equality and equal opportunity for welfare. *Philosophical Studies* 1989;56:77–93) and G. A. Cohen (Cohen GA. On the currency of egalitarian justice. *Ethics* 1989;99:906–44); and lately represented by, e.g., Andrew Mason (Mason A. *Leveling the Playing Field: The Idea of Equal Opportunity and Its Place in Egalitarian Thought*. Oxford: Oxford University Press; 2006).

17. Dworkin (Dworkin R. *Sovereign Virtue: The Theory and Practice of Equality*. Cambridge, MA: Harvard University Press; 2000, at 324) admits that the difference between choice and circumstance is a matter of degree, and that it might be difficult to identify whether a particular outcome, e.g., unemployment, is the result of chance or choice. Arneson (see note 16, Arneson 1989, at 79–82) mentions that the notion of preferences ought not to be simplified straightforwardly into the category of choices, because of the circumstantial origin of such preferences. Cohen (see note 16, Cohen 1989, at 922–34) argues that the conceptions of personality and expensive tastes cannot, in principal, be placed merely in the category of choice. And Mason (see note 16, Mason 2006, at 188–93) strongly emphasizes the influence that the different social structures have on "voluntary choices" as limiting elements of responsibility.
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27. See note 24, Azétsop, Rennie 2010; note 9, Smith et al. 2009.
28. See note 4, Daniels 2008.
29. Dupras C, Ravitsky V, Williams-Jones B. Epigenetics, and the environment in bioethics. *Bioethics* 2014;28(7):327–34.
30. See note 24, Azétsop, Rennie 2010.
31. See note 21, Whitehouse 2003.
32. See note 6, Jonsen 2001.
33. See note 6, Jonsen 2001, at 26–7.
34. For a thorough analysis of the argumentation involved in making better people, see Häyry M. *Rationality and the Genetic Challenge*. Cambridge: Cambridge University Press; 2010.
35. E.g., Savulescu J. Procreative beneficence: Why we should select the best children. *Bioethics* 2001;15(5–6):413–26; Harris J. *Enhancing Evolution: The Ethical Case for Making Better People*. Princeton, NJ: Princeton University Press; 2007.
36. See note 21, Wikler 1997. Norman Daniels was an influential initiator of the philosophical discussion relating healthcare and distributive justice. Daniels N. *Just Health Care*. Cambridge: Cambridge University Press; 1985.
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38. See note 21, Wikler 1997.
39. See note 6, Jonsen 2001.
40. See note 21, Whitehouse 2003.
41. International Bioethics Committee. *Report of the International Bioethics Committee of UNESCO (IBC) on Social Responsibility and Health*. Paris: Unesco; 2010.
42. See note 36, Daniels 1985. Daniels draws his analysis from Rawls J. *A Theory of Justice*. Cambridge, MA: Belknap Press of Harvard University Press; 1971.

43. See note 4, Daniels 2008.
44. See note 18, Daniels 2011.
45. For social scientific studies about the relation of one's socioeconomic position and course of life, see note 5, Wilkinson, Marmot 2003; Lynch JW, Kaplan GA, Salonen JT. Why do poor people behave poorly? Variation in adult health behaviors and characteristics by stages of the socioeconomic lifecourse. *Social Science and Medicine* 1997;44(6):809–19; Wilkinson RG, Pickett K. *The Spirit Level: Why More Equal Societies Almost Always Do Better*. New York: Bloomsbury Press; 2009.
46. See note 29, Dupras et al. 2014.
47. See note 4, Wikler 2002.
48. An important issue not discussed in this article is that the normative conception of health and well-being ought to be pluralistic enough. Overly intrusive standards of health are likely to result in ill-being in terms of moralistic decisions about various lifestyles, stress, discrimination, and wasted resources on excessive monitoring. As Daniels (see note 18, Daniels 2011) argues, more pluralistic approaches in health policy advance the public good of liberty, diversity, and even toleration and solidarity.