Special Section: Justice, Healthcare, and Wellness

The Quality Adjusted Life Year

A Total-Utility Perspective

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Abstract: Given that a properly formed utilitarian response to healthcare distribution issues should evaluate cost effectiveness against the *total* utility increase, it follows that any utilitarian cost-effectiveness metric should be sensitive to increases in both individual and social utility afforded by a given intervention. Quality adjusted life year (QALY) based decisionmaking in healthcare cannot track increases in social utility, and as a result, the QALY cannot be considered a strict utilitarian response to issues of healthcare distribution. This article considers arguments against, and a possible defence of, the QALY as a utilitarian concept; in response, the article offers a similar — but properly formed — utilitarian metric called the (IALY). This article also advances a tool called the 'glee factor' (GF) on which the IALY may lean in a similar way to which the QALY leans on the Rosser Index.

Keywords: QALY; IALY; utilitarianism; welfare distribution; social and political theory; healthcare distribution; glee factor; healthcare ethics; health economics; social utility

Introduction

The quality adjusted life year (QALY) was never, as far as I can tell, envisaged as a strict utilitarian response to decisionmaking issues within the healthcare system. Nevertheless, it is often thought of as such.[1] This article investigates the QALY and concludes that it cannot be understood as a utilitarian concept. In response, I advance: 'the inclusion adjusted life year' (IALY), as a more properly formed utilitarian metric; and the 'glee factor' (GF), as a measure of positive social feeling arising from inclusion of individuals into the local community. This article should, therefore, not be considered a critique in the usual sense.

Before turning to the QALY, I should indicate that I make a number of broad representations and acknowledge that the concepts to which I refer are more nuanced than presented here. For the purposes of this article, however, when I refer to the 'healthcare system', I am referring to the type of publicly funded system found in countries such as the United Kingdom, Finland, Canada, or Croatia, which provides a broad spectrum of medical services including surgeries, pharmaceuticals, aids, prosthetics, counselling, inoculations, and contraceptives. Similarly and importantly, when I refer to 'utilitarianism', I do not mean to specify any one particular formulation, but to refer (very broadly) to the fundamental principle of utilitarianism: *that actions or policies should be implemented on the principle of the 'greatest good to the greatest number'*. The 'greatest number' can be understood (at least for the purposes of this article) to refer to taxpayers and others in a given community.

The QALY

To make decisions about how 'best' to spend money in healthcare, Alan Williams argues that, "we need a simple, versatile, measure of success which incorporates

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both life expectancy and quality of life"[2] and that a "Quality Adjusted Life Year (QALY) measure fills such a role."[3] Calculation of the QALY is simple: the change in utility generated by any given intervention is multiplied by the time in which the individual is expected to experience the effects of the intervention.[4] Calculation of the QALY: "assumes that a year of life lived in perfect health is worth 1 QALY (1 Year of Life × 1 Utility = 1 QALY) and that a year of life lived in a state of less than this perfect health is worth less than 1. In order to determine the exact QALY value, it is sufficient to multiply the utility value associated with a given state of health by the years lived in that state."[5] The number generated by this calculus is the number of QALYs gained, and is expressed in terms of the number of "years lived in perfect health."[6] Specifically, it can be considered to be at once a measure of health improvement used to guide healthcare resource allocation decisions,[7] a metric of health effectiveness for cost-effectiveness analysis, and a heuristic for decisionmakers charged with allocating scarce resources across competing healthcare programs.[8]

I am by no means the first to offer criticism of the QALY, either as a utilitarian concept or as a decisionmaking metric in and of itself. Maurice McGregor and J. Jaime Caro, for example, observe that the QALY "enables direct comparison of the costs of obtaining different health outcomes through cost utility analysis"[9] — though whether or not such a comparison is practically achievable is the subject of much debate.[10] The increase (or decrease) in utility is estimated by medical professionals and, as such, is open to professional bias; relatedly, the calculation of the QALY prompts questions as to whose values are important.

Marta O. Soares engages the issue of differing values: "[The QALY] assumes that health improvement is equally valued between individuals — QALYs ignore how health gains are distributed across individuals. However, some may regard that there are fairer (thus more equitable) ways to distribute health gains: for example, those whose health is worse may be considered more deserving."[11]

Building on Soares's observations, it is also the case that people value different aspects of health, and accordingly, they privilege health improvements differently (disabled persons, for example, have a very different perspective on what constitutes a health improvement than do able-bodied persons). Steven Schwartz, Jeffrey Richardson, and Paul P. Glasziou, raise similar concerns by noting that: "The usual decision rule in a cost-utility analysis is to assign resources where they will maximise QALY gains. The greatest good for the greatest number (utilitarianism) is the underlying ethical premise."[12] They go on to observe that "each person's QALY is treated as being of equal value, QALYs do not reflect possible differences in the intensity of preferences (utility) between people"[13] and finish with the conclusion that "for this reason, the underlying ethic is better described as 'quasi-utilitarian.'"[14] Indeed, whether or not cost effectiveness should impinge on whether a person receives medical treatment at all has been widely discussed.[15]

Paul Dolan's 2001 article, "Utilitarianism and the Measurement and Aggregation of Quality Adjusted Life Years," however, attempts a more focused attack on the QALY *qua* utilitarian concept by weighing the QALY against a taxonomy of utilitarianism (which he defines as a "consequentialist, monist, welfarist, preference-based philosophy in which advantage is aggregated according to sum-ranking").[16] He concludes that "the QALY *in principle* … strictly satisfies two out of five conditions; consequentialism and monism."[17] He continues with the observation that the

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perception of the QALY as a utilitarian concept is probably related to the simple fact that "the QALY concept is often seen to be synonymous with QALY Maximisation," which itself is partly a function of "the fact that *in practice* most empirical studies [aggregate] the QALY in this way."[18]

Maximising Utility and A Short Defence of The QALY

I shall not, here, present a deep analysis of utilitarianism; however, some support for the interpretation adopted in this article should be offered. The opening paragraph from Jeremy Bentham's *Introduction to the Principles of Morals and Legislation* clearly sets out the fundamental principle of Utilitarianism: "By the principle of utility is meant that principle which approves or disapproves of every action whatsoever according to the tendency it appears to have to augment or diminish the happiness of the party whose interest is in question: or, what is the same thing in other words, to promote or to oppose that happiness. I say [this] of every action whatsoever, and therefore not only of every action of a private individual, but of every measure of government."[19]

It should be pointed out that the discussion of what is actually meant by 'utility' is a long one, and is extensively covered by other authors.[20] For the purposes of this article, I shall understand 'utility' very broadly to mean 'happiness' (as happiness is partly a function of health and a reduced financial burden).

Jeremy Bentham and John Stuart Mill offer (what is now known as) classical utilitarianism as a comprehensive moral theory[21] — though Utilitarianism is perhaps *most* relevant today in relation to normative ethical theory. Although I might run the risk of blurring the concept of utilitarianism employed in this article, it might be pertinent to note that, at the level of political morality, the principles of utilitarianism apply to "what John Rawls calls 'the basic structure' of society, not to the personal conduct of individuals."[22] Will Kymlicka's clarification that Utilitarianism does not respond at the level of the individual is relevant to this article: Given that, a fundamental axiom of utilitarianism defines, "a morally right act or policy [as] that which produces the greatest happiness for the members of a society" and does not concern itself with the individual,[23] a *proper* utilitarian response to issues of healthcare distribution must consider whether or not (and to what degree) the cost of the treatment would increase the social utility to a community.

A Short Defence of the QALY as a Utilitarian Concept

I am gently persuaded by one potential avenue of thought, however: perhaps the QALY *could* pass as a utilitarian concept, if two implied assumptions are accepted. First, that the utility to a community is *in* the provision of a healthcare system upon which all those in society may call *when* needed (that having access to healthcare is, in itself, a sort of '*potential utility*') and, second, that this potential utility is equal to utility in the usual sense. With respect to the former, once it is accepted that there is a potential utility in healthcare, it demands that people should care that healthcare resources are managed properly (such that they are still able to provide services to all as and when required). With respect to the latter, it is necessary that the society view this potential utility as a full utility when comparing it to other more imminent utilities (such as a tax reduction).

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In support of this second assumption, I wonder if 'potential utility' could be subsumed under Frank Hahn's observation that "utility may not only depend on what I get but on the manner in which I get it. That is to say that, my utility may not only depend on the consequences of policy but on the policy itself."[24] Despite Hahn, however, I still do not feel that this sort of defence is enough: the QALY cannot be considered a utilitarian metric, because the increased or decreased utility (in health) of *one individual* is not, generally speaking, the sort of thing that is calculated by utilitarian metrics.[25] Amartya Sen and Bernard Williams similarly note that "once note has been taken of a person's direct utility, Utilitarianism has no further direct interest in any information about him."[26]

In other words, utilitarianism cares about the aggregate increase or decrease in utility from a particular action, not whether or not the individual alone gets an increase in utility. Conversely, the QALY reports only on the increase in utility to the individual; whatever utility the taxpayer gets from funding medical interventions cost effectively is merely a happy accident. *This* observation, then, stands as the most obvious and damning blow to the QALY as a utilitarian concept: the QALY is only able to serve the utilitarian mantra 'greatest good for the greatest number' in the sense that it seeks to indicate which medical interventions provide the greatest QALY increase for the minimum amount of taxpayers' money. To be a properly formed *utilitarian* concept, however, it is not enough that the negative utility (cost) to those who pay for the healthcare system is offset solely by the provision of healthcare to those who need it.

Structurally, therefore, the QALY seems to be improperly geared to track the social utility afforded by performing a particular intervention on a particular individual where the social utility is utility that accrues to 'the greatest number.' Sen and Williams summarise the issue well: "persons do not count as individuals in [the calculation of negative utility and utility] any more than individual petrol tanks do in the analysis of the national consumption of petroleum."[27] For the QALY to be a *properly* formed utilitarian concept, it should track the increase in *social* utility (say, to the taxpayers) from that medical intervention (which constitutes a negative utility), not an increase in *individual* utility.

The IALY

Concurring with scholars such as Paul Dolan and Steven Schwartz, I think it is clear that the QALY can only be considered a utilitarian concept in the naïve sense that it seeks to evaluate the increase in utility to an individual against the negative social utility from funding that intervention. This fact, however, does not imply that utilitarianism is structurally *unable* to offer a QALY-like metric (though any utilitarian metric will fall foul of arguments that can be made against utilitarianism itself, and will likely generate the usual sort of unpalatable responses). Nevertheless, below, I shall present such a utilitarian metric: the IALY. Before doing so, however, I feel that a brief discussion of inclusion is warranted.

The word 'inclusion' has most recently been associated with the disability rights movement (DRM), who use the word to refer to the idea of open accommodation for people with impairments (such open accommodation is achieved by the provision of ramps, equal employment, and education opportunities, for example). However, at the heart of the DRM effort is a desire to establish a society whose members have equal opportunity to work, travel, interact, socialise, and otherwise

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live full lives: a society that is fully *inclusive*. When I use the term 'inclusion,' what I mean to identify is the notion of being an active part of a community in whatever ways are preferential. Persons who experience ill-health, for example, may not be able to go grocery shopping, go to work, or go to a park with their children. This reduced interaction with the society constitutes a sort of ill-health-generated exclusion. The return to better health may afford greater (but not necessarily full) health. Thus, what a person experiences as a function of greater health is greater inclusion — in the sense that this person is more 'included' in activities that a society privileges.

The DRM have long opined that greater inclusion benefits society as a whole, and in a way, the DRM's 'inclusion' is about 'full integration' in society. Textual justification for this claim is not without its difficulties, but what little data are available show how societies seem to be (at least financially) better off when previously excluded members of that society experience greater levels of inclusion.[28] One is trepidatious about making a correlation between wealth and happiness; but wealth aside, returning to a healthier state carries with it a self-evident increase in utility (both to the individual and to the community). This 'return to a previous level of activity' can also be construed as a form of greater inclusion (where ill-health may exclude an individual from certain everyday activities such as playing with the children, grocery shopping, or working) and can similarly be presumed to benefit both the individual and the society of which that person is a part.

As its name suggests, the IALY measures the increase in social utility afforded by a person's greater inclusion in a society. Greater inclusion is afforded by a return to better health, which is, in turn, afforded by a medical intervention. Relatedly, the intervention can be understood as a decrease in social utility in the form of taxation. As a utilitarian metric, then, the IALY is charged with evaluating the increase in social utility afforded by a given medical intervention against the decrease in social utility experienced by funding that intervention. However, because there is a correlation between greater inclusion in a society and ones' quality of life, the IALY *can* be used to infer an estimated increase in quality of life to an individual simply by tracking the increased social utility as a function of that person's return to greater inclusion.

The discussion of what 'full inclusion' might mean is a problematic one. From the medical perspective, full inclusion would probably imply a return to a 'normal' level of social interaction and activity; however, this description raises the debate over what is meant by 'normal.' There is little space in this article to respond appropriately to this important question — but to sate the reader's (quite reasonable) demand for clarity, I would suggest that 'normal' in this case would refer to whatever level of social activity was enjoyed by the individual prior to ill health (though this, I accept, then begets a question about the nature of ill health). At the very least, I would be comfortable with the idea that whatever is meant by 'full health' for the QALY is probably not far off from what is meant by 'full inclusion' for the IALY. A *properly formed* Utilitarian cost-effectiveness metric should consider whether or not (and to what degree) the cost of a given intervention would increase social utility.

The calculation of the IALY is almost identical to that of the QALY, and assumes that a year of life lived in perfect health and in full inclusion is worth 1 IALY (1 Year of Life × 1 Utile of Inclusion = 1 IALY) and that a year of life lived in a state of less than perfect inclusion due to ill-health or exclusion is worth less than 1. In order to

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determine the exact IALY value, it is sufficient to multiply the utility value associated with a given state of full inclusion by the years lived in that state.

The number generated from an IALY calculus is the number of IALYs gained, and is expressed in terms of the number of years lived as a fully included member of society (this number will, unlike the QALY number, appropriately lower as an individual ages). To paraphrase Williams, I believe that such a calculus needs to be a 'simple, versatile, measure of success which incorporates life expectancy and quality of life,' and I believe that the 'Inclusion Adjusted Life Year measure fills such a role'.

Because the IALY evaluates not only how much utility would be experienced by the community from a medical intervention, but also how much more inclusion the intervention would generate for the individual, the IALY is more suited to evaluate the cost-effectiveness of funding of mobility aids, supplemental healthcare activities (such as counselling or return-to-work programs), and infrastructure investments. In this way, the IALY is able to reflect not only medical activities, but also those community infrastructure developments at the local government level which fund the provision of kneeling busses, chirping crosswalks, ramp access, sign interpreters, the generation of community integration officer positions, etcetera. As a result, the remit of the IALY is greater than that of the QALY, and might accordingly be considered a more flexible tool.

Criticisms

The QALY has received a fairly significant level of criticism in the literature, and it seems that the IALY improves on some aspects of those criticisms. For example, the IALY does not hinge-upon some definition of 'perfect health'[29] (though it does require some definition of full inclusion); Dolan's concerns about health states that are worse than death[30] also do not apply. Similarly, Erik Nord's concerns about the overall distribution of health states[31] are less concerning, because the IALY number drops off accordingly as a person gets older (as a result of reduced mobility impinging on that person's ability to actively engage in community activities). Joseph S. Pliskin's concerns over assumptions about risk-neutral behaviour[32] (the QALY calculus is run without reflection on the risk preferences of the individual) also do not seem to apply, as the increase in quality of life to the individual is only evaluated indirectly. In contrast, the IALY concerns itself with the social utility afforded by an intervention and, therefore, a person's risk behaviour is irrelevant to the outcome. Finally, a recent and strong criticism of the QALY by the European Consortium in Healthcare Outcomes and Cost–Benefit Research (ECHOUTCOME), identifies that participant responses about heath states do not match QALY theoretical assumptions.[33] This criticism is specific to the QALY and, thus, cannot apply to the IALY (though it would be interesting to run the survey on the IALY to see if its theoretical assumptions mirrored the participants's preferences more closely).

It should be emphasised that the IALY is not offered here as a flawless concept. As mentioned earlier, the ostensible arguments made against utilitarianism may be equally made against the IALY (given that it stands as a utilitarian tool). As an example, the IALY and the GF seem to indicate that working, socially active individuals with larger families generate a higher IALY number from any given intervention than would retired, socially introverted individuals with smaller families. This seems to be clearly unfair; nevertheless, the kind of consequentialism generated

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by utilitarianism can generate results which our everyday moral intuitions find jarring.[34] To these intuitions, for example, it seems irrelevant, that an individual's receiving a medical intervention should have anything at all to do with whether or not the rest of society is any better off from such an intervention. Utilitarianism, however, cannot permit our moral compass to guide its decisionmaking — the point of the utilitarian axioms is to overrule those impinging moral niggles in favour of axioms that aggregate utility to the greatest number. In this respect, then, the IALY and the GF are not without fault — given a Utilitarian milieu, though, they seem to hold under (at least) moderate scrutiny. The thrust of this article is not that the IALY is a 'fix-all' solution to welfare distribution, but that it stands as a proper utilitarian concept in the way that the QALY does not. That the IALY responds better to the arguments laid previously against the QALY is merely serendipitous.

The GF

From what has been said, it seems that were some utilitarian measure of cost-effectiveness to be formed, it would need to be sensitive to an increased level of inclusion; but measuring inclusion is a difficult matter, and thus a tool is required: The IALY operates in almost exactly the same way as the QALY, and in the same way that the QALY leans on the Rosser index (and its descriptive classification of disability/distress states and their associated valuations),[35] the IALY leans on the GF. I loosely define the GF as 'the positive social feeling arising from full inclusion of individuals into the local community' (and by extension, society as a whole). This measure can be employed by the IALY to determine the possible increase in social utility resulting from a potential medical intervention.

I shall consider two hypothetical medical cases.

(1) Gerry

- 70 years old; retired; few friends; not actively engaged in any groups, clubs, or community activities
- Married; three grown children; 4 grandchildren
- Needs a femoral artery replacement
- Current QALY rating is 0.5
- Surgery will permit him to reach a QALY figure of 0.8
- Cost of Intervention $200,000

(2) Paul

- 70 years old; professor; many friends; actively engaged in groups, clubs, and community activities
- Married; one grown child; no grandchildren
- Diabetic and needs a hip replacement
- Current QALY rating is 0.5
- Surgery will permit him to reach a QALY figure of 0.8
- Cost of Intervention $200,000

The QALY calculus is unable to indicate a preference for one case over the other, as they both result in the same increase in utility to the individual and they both cost the same amount of money. An IALY evaluation, however, would take into consideration the increase in social utility afforded by the intervention.

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Encompassed within the GF is the wealth of feeling demonstrated by acts of inclusion (such as the party thrown by Osceola County for an autistic 6-year-old[36] and the "Hearing Hands" program by Samsung;[37] both of which have received much acclaim on social media networks). The GF is sensitive to not only the financial ramifications of inclusion, but also the happiness, feeling of unity, community togetherness, and internal and external validation that comes from proper and full inclusion. These factors cumulate to form a profound and positive effect — a utility — for the 'greatest number.' The GF is distinct from the 'ripple effect', which is most often typified as the financial dividend to a society reaped as a function of an individual's contributing to the welfare burden. Given that utilitarianism focuses on the total increase in utility (which I have presented, broadly speaking, as social utility), I maintain that the GF also stands as a utilitarian tool and is, thus, a suitable tool for the IALY.

Evaluating the above mentioned cases in light of the GF, it would be reasonable to assume that Paul has a greater influence on the community than Gerry: he is part of many community events and groups, and is actively engaged in the development of new minds at a university. Gerry, as a retired individual, is not involved with community events and has a much smaller GF 'footprint'. This is not to say that Gerry does not generate social utility, but rather that whatever influence in terms of utility he has is largely restricted to his family and friends. Yet, it is equally possible that the social utility experienced by Gerry's extended family may be greater than that of the social utility provided by Paul; such a calculus is not without its difficulties. One such difficulty is that the GF seems as though it might churn out different results as a function of being somewhat culturally relative (in that some cultures might privilege family over academic development). I see no reason to presume, however, that this relativism would harm its usefulness as a tool for the IALY.

Under the QALY, both individuals in the cases described would receive the same utility from their respective medical interventions: an increase of 0.3 QALY. However, under the IALY, both cases generate a social utility increase once the individual reaches better health and return to the community (prior to becoming healthier, they both constitute a negative social utility, in that they are a drain on resources and a worry to friends and family). In Gerry's case, he is able to be more active with his family and is able to better assist with house chores. Although he is retired and does not contribute work or tax revenue to society, his retirement means that he has more time to assist with the care of the grandchildren — permitting his children to focus more on their work and to potentially increase their tax contributions. As such, Gerry's GF footprint can be seen to be fairly significant. Paul has an active career as a professor and helps advance knowledge by writing and teaching. He is also a member of community activities and university groups, and interacts with many people because of this. However, he is likely to retire soon and has a small family and no grandchildren; when he retires, it is likely that he will become much less engaged in university activities and groups, at which point (and because of his diabetes, which indicates the potential for further health issues in the future), Paul's social utility will probably become lower than Gerry's. These external-to-the-individual utilities are important from a utilitarian perspective, as they say more about the influence an individual has on their community, and advise on the social utility generated by their treatment. The GF is intended to quantify those social utilities for use in the IALY metric.

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Conclusion

This article presents criticisms of the QALY as both a metric and as a utilitarian concept as they appear in the literature, and offers a further criticism of the QALY as a utilitarian concept. It concludes that the QALY fails to be a properly formed utilitarian concept because it is unable to evaluate the social utility afforded by a given intervention. This paper then continues to briefly discuss an interesting possible avenue of defence for the QALY, followed by a refutation.

This article advances an alternative to the QALY called the IALY, which focuses on the increased social utility afforded by an individual's receiving a medical intervention which increases that person's inclusion in a community. The IALY is similarly formed to the QALY, but improves on the latter by tracking both social utility and (though indirectly) the increase in quality of life of a specific individual. As a measure of the value of a certain medical intervention, the IALY more accurately reflects the social utility that comes from an individual's being more actively included in a community, and provides a more accurate assessment of the utile dividend to that community from funding a particular healthcare activity. Such a metric evaluates not only how much utility would be experienced by the community from a medical intervention, but also how much more inclusion the intervention would engender. Because the IALY is able to reflect not only medical activities, but also community infrastructure developments at the local government level, it stands as a much more flexible and multi-use metric.

The GF was developed to serve the IALY in the same way that the Rosser Index serves the QALY, but instead of calculating distress states, the GF is used to measure the positive social feeling arising from an individual gaining greater (or full) inclusion into a community. The GF can be roughly defined as the delight/elation felt when certain positive social media posts are read. Unlike the ripple effect, the GF is also sensitive to non-financial social utility generated by an individual's returning to a community.

The IALY carries with it the added potential of evaluating the increased utility distribution to a community from funding inclusion programs — rather than being restricted to only evaluating the utility to the individual from some given medical intervention. The increased community utility metric could be achieved by simply changing the parameters of the IALY calculus to provide a measure of utility to a community from any given expenditure on inclusion programs.

Finally, this article offers the IALY and the GF as properly formed utilitarian concepts, and acknowledges that (within a utilitarian milieu) the IALY and the GF stand as useful tools to resolve issues of healthcare distribution. However, I also acknowledge that, because the IALY and the GF are utilitarian concepts, they are also subject to criticisms of utilitarianism itself. It is difficult to avoid utilitarian criticisms when attempting to develop a utilitarian concept, and the reader is urged to understand that the IALY is not here offered as a flawless response to issues of healthcare distribution, but rather as a properly formed theoretical Utilitarian concept. Finally, this article notes that some of the non-utilitarian criticisms that have plagued the QALY seem less potent against the IALY.

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Notes

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17. See note 1, Dolan 2001.
18. See note 1, Dolan 2001, at 67.
19. Bentham, J. Chapter 1: Of the principle of utility. In: *An Introduction to the Principles of Morals and Legislation*. Mineola, NY: Dover Publications; 2007.
20. See, for example, Kymlicka W. *Contemporary Political Philosophy: An Introduction*. New York: Oxford University Press; 2002.
21. See note 20, Kymlicka 2002, at 10.
22. See note 20, Kymlicka 2002.
23. See note 20, Kymlicka 2002.
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