Investing in Justice

Investing in Justice: Ethics, Evidence, and the Eradication Investment Cases for Lymphatic Filariasis and Onchocerciasis

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It has been suggested that initiatives to eradicate specific communicable diseases need to be informed by eradication investment cases to assess the feasibility, costs, and consequences of eradication compared with elimination or control.

A methodological challenge of eradication investment cases is how to account for the ethical importance of the benefits, burdens, and distributions thereof that are salient in people's experiences of the diseases and related interventions but are not assessed in traditional approaches to health and economic evaluation.

We have offered a method of ethical analysis grounded in theories of social justice. We have described the method and its philosophical rationale and illustrated its use in application to eradication investment cases for lymphatic filariasis and onchocerciasis, 2 neglected tropical diseases that are candidates for eradication. (*Am J Public Health.* 2015;105:629–636. doi:10.2105/AJPH.2014.302454)

THE ERADICATION OF SMALLPOX was a signature success of global public health in the 20th century, but it is an open and contentious question whether global eradication as opposed to regional elimination or control is warranted for other potentially eradicable infectious diseases.[1–4] The box on page 630 provides our definitions of eradication, elimination, and control, as explained by Dowdle.[4]

Global eradication efforts require vast resource commitments that must be locked in over long time frames, thereby imposing opportunity costs that require justification. For example, donors invested $10.0 billion in the Global Polio Eradication Initiative from 1988 through 2012, and the Global Polio Eradication Initiative's 2013 to 2018 strategic plan calls for an additional $5.5 billion, totaling $15.5 billion over 30 years.[5] The Global Polio Eradication Initiative has prepared an economic case estimating net benefits to date at $27.0 billion and arguing that completion of the eradication initiative would be more cost effective than are available alternatives.[6] Ideally, with so much at stake, deliberations about coordinated global approaches to eradicable infectious diseases should be informed by prospective comparative assessment of the feasibility, costs, and consequences of control, elimination, and eradication. The same point of principle applies to other large-scale, long-term, and resource-intensive health programs, substituting the relevant scenarios for comparison.

The eradication investment case (EIC) framework is a method for making such assessments to apply them to eradicable infectious diseases.[7–11] Although traditional health and economic assessments are core components of EICs, leading architects of the EIC framework contend that EICs should also include "a narrative of the moral value of launching an eradication program" to "capture the value of intangible benefits and ensure consideration of benefits that are difficult to quantify."[9(p143)] EICs lacking such ethical analyses may critically overvalue or undervalue eradication scenarios compared with elimination or control by failing to identify ethically important kinds of benefits, burdens, and distributions thereof. The need for such prospective ethical analysis is not unique to assessing disease eradication programs and arguably should be part of assessing and justifying other kinds of health programs.

How can EICs account for the ethical importance of the benefits, burdens, and distributions thereof that are salient in people's experience of particular diseases and disease-related interventions but not assessed in traditional health and economic evaluations? We have proposed a method of ethical analysis grounded in social justice to help EICs respond to this challenge in hopes that it may also prove useful as an approach to prospective ethical assessment for health programs concerned with noneradicable infectious diseases and noninfectious diseases. We have illustrated the proposed method through its application to lymphatic filariasis and onchocerciasis, 2 neglected tropical diseases considered amenable to eradication and for which EICs are currently being assembled.[7]

LYMPHATIC FILARIASIS AND ONCHOCERCIASIS

Lymphatic filariasis is an infection caused by *Wuchereria bancrofti, Brugia malayi,* and *Brugia timori* worms that are transmitted by mosquitoes and black flies.[12] Its clinical manifestations include

Definitions of Eradication, Elimination, and Control

Eradication—the permanent reduction to zero of the worldwide incidence of infection caused by a specific agent as a result of deliberate efforts so that intervention measures are no longer needed.

Elimination—the reduction to zero of the incidence of infection caused by a specific agent in a defined geographical area as a result of deliberate efforts; continued measures to prevent reestablishment of transmission are required.

Control—the reduction of disease incidence, prevalence, morbidity, or mortality to a locally acceptable level as a result of deliberate efforts; continued intervention measures are required to maintain the reduction.

Source. Dowdle.[4]

acute inflammatory episodes as well as chronic illnesses of lymphedema, elephantiasis, and hydrocele. It occurs in tropical regions of the Americas, Asia, and Africa. Approximately 120 million people worldwide are infected, with 40 million disfigured or debilitated by chronic disease: 15 million with lymphedema and 25 million with hydrocele. In many settings, prevalence and disease burden have been reduced through concerted efforts in vector control and mass drug administration, relying on ivermectin in Africa and diethylcarbamazine citrate in other regions, both now usually coadministered with albendazole.[13]

The eradication of lymphatic filariasis would involve scaling up annual mass drug administration in each lymphatic filariasis–endemic region, achieving greater than 65% coverage of at-risk populations and maintaining it for up to approximately 6 years, depending on local epidemiology, vector fauna, and other factors.[14] Thereafter, regular surveys and surveillance are required to detect recrudescence.[14] These forecasts hold at a country level only if all endemic areas are treated simultaneously. In practice, however, this is not generally the case. Some countries have yet to complete mapping activities to determine the endemicity and distribution of lymphatic filariasis; some have not yet begun mass drug administration; and many others are currently targeting relatively small proportions of their at-risk populations. In consequence, lymphatic filariasis eradication will require huge efforts to scale up mass drug administration coverage.

Onchocerciasis is an infection caused by the worm *Onchocerca volvulus* in conjunction with *Wolbachia*, an endosymbiotic bacterium.[15] Onchocerciasis is transmitted by black flies. Its most common clinical manifestations are a variety of chronic disfiguring skin disorders involving skin thickening, lesions, rash, depigmentation, and profoundly severe itching with compulsive scratching. Less common (<10% of all cases) is its notorious manifestation as the second leading infectious cause of vision impairment and blindness worldwide (known as "river blindness"). Onchocerciasis is clustered in Africa. Approximately 25 million people worldwide are infected with *O. volvulus,* of whom 300 000 have suffered blindness and 800 000 have some degree of vision loss. Onchocerciasis can be treated with ivermectin or doxycycline. In certain endemic countries, people with onchocerciasis may also be infected with Loa loa and as a result experience a dangerously severe adverse reaction to ivermectin. Doxycycline does not cause this reaction in people with Loa loa and is the preferred treatment in such countries. Recent studies in some hyperendemic West African foci have proven the feasibility of onchocerciasis elimination through a strategy of community-directed treatment with ivermectin or doxycycline in Loa loa–endemic countries, with treatment administered once or twice yearly for an estimated 8 to 25 years to at least 70% of the population.[16,17]

For purposes of the EIC, the scenario of moving toward onchocerciasis elimination builds on the current community-directed treatment with ivermectin strategy, extending coverage to all areas where there is local transmission (defined as a nodule prevalence > 5%, whereas interventions have traditionally focused on areas with a nodule prevalence > 20%) and sustaining mass treatment up to demonstrated elimination in the entire focus.[7,15] Thereafter, periodic epidemiological and entomological surveys as well as passive surveillance need to be maintained pending eradication. Maintaining mass treatment of the required duration is a major challenge in countries with weak governance and poor health system capacity.[7,15]

A METHOD OF ETHICAL ANALYSIS GROUNDED IN SOCIAL JUSTICE

In the preparation of EICs for lymphatic filariasis and onchocerciasis, 1 step toward accounting for a fuller spectrum of ethically important benefits and burdens has been to conduct a systematic review of empirical literature documenting the psychological, psychosocial, and social impacts of these diseases (data available as a supplement to the online version of this article at http://www.ajph.org).[18] A method of ethical analysis is still needed to support the comparative assessment of such impacts across different scenarios in the EICs. Ideally, this method should strengthen EIC-supported

deliberations by (1) delineating ethically important categories of benefits and burdens not otherwise captured in the EIC framework, (2) assessing aspects of distributive equity and fairness not otherwise captured, (3) recognizing widely varying life circumstances among people affected by the diseases and interventions, and (4) ethically interpreting the evidence base concerning disease-specific psychological, psychosocial, and social impacts.

Social justice consists in fairness and equity in the distribution of societal benefits and burdens.[19] A commitment to social justice in this broad sense is central to public health.[20–22] Policy choices involving social justice sometimes present trade-offs between maximizing aggregate net benefit and alleviating profound or pervasive social disadvantage.[19,23–29] Neglected tropical diseases such as lymphatic filariasis and onchocerciasis are concentrated among lower-income countries and disadvantaged populations.[30] Global programs to address neglected tropical diseases are signal examples of public health interventions that may change the life prospects of people who bear the heaviest burdens of pervasive disadvantage.[30]

Considerations of social justice are thus inescapably critical to the decisions about global priority setting and resource allocation that EICs are meant to inform. Accordingly, our proposed method of ethical analysis for the assessment of psychological, psychosocial, and social impacts in EICs is grounded in contemporary philosophical theories of social justice. For policy choices that pose hard questions of social justice, such theories offer a principled basis for deliberation by providing, in the words of Daniels,

> a moral structure that gives weight to some kinds of deficits in well-being and not to others. It favors some reasons for assisting persons and considers others irrelevant.[29(p33)]

An influential recent trend in scholarly work on social justice has been the development, defense, and use of theories of justice derived from multidimensional metrics of human well-being.[23–25,31–35] Proponents of these theories argue that people who hold varying worldviews and value systems have reason in common to regard several distinct dimensions of well-being as matters of fundamental ethical importance because they are each basic determinants of the character and quality of human life.[23,35] The implication for social justice is that institutions, programs, and policies ought to be evaluated in light of the nature and distribution of their impacts on each of these multiple dimensions of well-being. The principles that should govern the distribution of impacts in different dimensions of well-being vary among these theories of justice and can include principles of equality, sufficiency, and prioritization.[23–25,35] This general approach to social justice is used in the ethics of international development[31–33,35] and has been specifically adapted to issues of health in the writings of Daniels, Powers and Faden, Prah Ruger, and Venkatapuram.[23,25,29,34]

Theories of social justice using multidimensional metrics of well-being offer a promising approach to accounting for ethically important psychological, psychosocial, and social impacts in EICs. In attributing fundamental ethical value to each of the basic dimensions of well-being that affect the quality of human lives across widely varied conceptions of the good life, this approach to social justice has fair claim to support a maximally broad consensus among people with different national, cultural, and personal backgrounds. Breadth of consensus is a matter of great importance in the EICs and for related global policy choices about eradicable infectious diseases considering the wide range of individuals and groups who stand to be involved or affected.

A CORE FRAMEWORK OF SOCIAL JUSTICE

We propose a core framework of social justice predicated on 3 dimensions of well-being—agency, association, and respect—and 1 principle of justice: that it is a priority and duty of justice to avert and alleviate clusters of disadvantage in multiple dimensions of well-being. We chose each component of our core framework in virtue of its being a point of convergence or overlap among multiple theories of social justice that use multidimensional metrics of well-being. Assembled in this way, our core framework is arguably less contentious than any single theory would be as a basis for public social deliberation and decision-making and so offers a correspondingly more compelling normative framework for ethical analysis in EICs. A core framework of justice composed of points of overlap among multiple theories arguably has more robust stability and salience for ethical assessments than do the relatively more controversial elements of those theories that lack plural grounding in multiple theories.[36]

Agency is the ability to lead one's own life and engage in activities one finds meaningful. Across multiple theories of social justice, agency has fundamental ethical importance as a basic dimension of human well-being. In Daniels's theory of social justice and health, following John Rawls's more general theory of justice, a fundamental aim of justice is to enable and sustain individual agency through the provision of civil liberties, fair equality of opportunity, and resources needed to lead a good life (under widely varying conceptions of what makes for a good life).[26–29] For Nussbaum—and for Wolff and de-Shalit and Venkatapuram, whose works adopt Nussbaum's delineation of 10 core human capabilities—agency has fundamental ethical importance in the form of 2 capabilities: practical reason and control over environment.[24,25,35] For Powers and Faden, agency has fundamental ethical importance in the form of self-determination as a core dimension of human well-being.[23]

Association is the ability to engage in a full range of intimate, familial, friendly, community, economic, and civic relationships with other people. For Nussbaum, Wolff and de-Shalit, and Venkatapuram, association is a subcomponent of the overarching core

human capability for affiliation.[24,25,35] For Powers and Faden, association understood as attachment is a distinct core dimension of human well-being.[23]

Respect is the recognition, by others and oneself, of one's equal moral value, worth, and dignity as a person. For Daniels, following Rawls, respect counts among primary goods in the form of the "social bases of self-respect."[26–29] For Powers and Faden, respect is a distinct core dimension of human well-being.[23] For Nussbaum, Wolff and de-Shalit, and Venkatapuram, respect is (along with association) an explicitly delineated subcomponent of the overarching core capability for affiliation.[24,25,35]

A fourth point on which multiple theories converge is a shared principle of prioritization, by which it is a priority and duty of justice to avert and alleviate clusters of disadvantage involving multiple dimensions of well-being. As Powers and Faden argue, justice requires that priority be given to addressing systematic disadvantages that cut across multiple core dimensions of well-being.[23] Wolff and de-Shalit argue for a duty to prioritize social institutions, programs, and policies that "decluster disadvantage," breaking up vicious cycles through which disadvantages in some dimensions of well-being coexist with and reinforce disadvantages in other dimensions.[23] Venkatapuram has also endorsed this norm of declustering disadvantage in his writings on justice.[25] As applied to decision-making in public health, the prioritization norm of declustering disadvantage requires comparing programs and policies with respect to whether they address such especially hurtful and inequitable distributions of impacts on well-being.

The core framework assembled from these 4 points can guide the assessment of psychological, psychosocial, and social impacts in the EIC for a particular disease as follows. The first step is to examine the empirical evidence on disease-related impacts on agency, association, and respect as dimensions of well-being that have fundamental ethical importance as a matter of justice. The second step is to ask how these impacts might create or exacerbate clusters of disadvantage involving multiple dimensions of well-being. It is important to distinguish clearly between the question of how disadvantaged the people most likely to be affected by lymphatic filariasis and onchocerciasis are and how much disadvantage lymphatic filariasis and onchocerciasis themselves cause. The third step is to compare the EIC's projected scenarios of control, elimination, and eradication with respect to addressing the duty to avert and alleviate clusters of disadvantage.

IMPACTS ON AGENCY, ASSOCIATION, AND RESPECT

We have examined the empirical evidence on psychological, psychosocial, and social impacts of lymphatic filariasis and onchocerciasis as systematically reviewed by Muela and Hausmann-Muela (data available as a supplement to the online version of this article at http://www.ajph.org).[18] The compiled evidence indicates that both diseases have adverse impacts on agency, association, and respect through several distinct mechanisms that appear closely interconnected (Tables 1 and 2).

Agency is diminished by physical incapacity and exclusion from opportunities for activity and achievement. Association is curtailed by ostracism, discrimination, and sexual impairment. Respect is adversely affected by stigma and experiences of teasing, ridicule, shame, low self-esteem, inferiority, and impaired satisfaction of gender norms. Moreover, people living with lymphatic filariasis or onchocerciasis actively withdraw from certain activities and associations in the attempt to pass as unaffected and avoid ostracism and stigma. Such disease-imposed trade-offs between dimensions of well-being (e.g., agency vs association, association vs respect) are themselves an important form of disadvantage.[24]

DISEASE-ASSOCIATED CLUSTERS OF DISADVANTAGE

Regarding the question of how disadvantaged the people most likely to be affected by lymphatic filariasis and onchocerciasis are,

TABLE 1—Impacts of Lymphatic Filariasis on Agency, Association, and Respect

Dimension	Disease-Related Impact	References
Agency	Physical incapacity from acute or chronic lymphatic filariasis syndromes	37–55
	Exclusion from opportunities for activity or achievement	37,42,44,53,55–58
	Impaired educational participation or performance	39,55,59,60
	"Passing" or avoidance of opportunities for activity or achievement	39,41,55,61
Association	Ostracism, discrimination, rejection, or avoidance of lymphatic filariasis–infected individuals or their contacts	41,44,46,47,53,56,61
	Difficulty attaining marriage or marital problems	37,47,53,56,59
	Impairment of sexual relations or sexuality	42,47,55,62,63
	Avoiding gatherings or other forms of social contact	37,39,59
Respect	Stigma, teasing, or ridicule	37,63–66
	Exclusion from leadership positions	37,44
	Being feared as directly contagious	53
	Experiencing shame, embarrassment, low self-esteem, or inferiority	47,55,59
	Impaired sense of meeting sexual and gender norms	63

TABLE 2—Impacts of Onchocerciasis on Agency, Association, and Respect

Dimension	Disease-Related Impact	References
Agency	Physical incapacity from onchocerciasis skin diseases or blindness or visual impairment	67–77
	Exclusion from opportunities for activity or achievement	69,76,78
	Impaired educational participation or performance	79
	"Passing" or avoidance of opportunities for activity or achievement	77,79
	Abandonment of fertile areas to avoid infection	69,73,80,81
	Compulsive and self-destructive behavior	79
Association	Ostracism and avoidance of onchocerciasis-infected individuals or their contacts	70,74,76,78,82
	Difficulty attaining marriage or marital problems	70,72,77,83–86
	Impairment of sexual relations or sexuality	76
Respect	Stigma, teasing, or ridicule	64–66,76,78,83,87–91
	Exclusion from leadership positions	62,68,70,76
	Being feared as directly contagious	92
	Loss of social status	70
	Negative stereotypes	70,76
	Experiences of shame, embarrassment, low self-esteem, or inferiority	76,83,84

these diseases typically burden people in lower-income countries who already face clusters of entrenched disadvantage associated with severe poverty and social exclusion.[30] Regarding the question of how much disadvantage lymphatic filariasis and onchocerciasis themselves cause, the diseases worsen the plight of affected people in 2 ways: they attack individual dimensions of well-being that have fundamental ethical importance as a matter of justice (agency, association, and respect), and they act as corrosive disadvantages in the sense that they produce clusters of coexisting and even mutually reinforcing disadvantages across all 3 dimensions.[24]

Adverse impacts across all 3 dimensions often arise from the same broadly disadvantaging disease symptoms, such as the disfiguring lymphedema caused by lymphatic filariasis and blindness caused by onchocerciasis, which are at once debilitating and bases of stigma, ostracism, and discrimination. Moreover, adverse disease impacts in a particular category may engender, interact with, and worsen disadvantages in the other categories. For instance, lymphatic filariasis–related hydrocele can curtail association by creating sexual impairment that hinders a man's attainment of marriage, thereby undermining respect through loss of social status because of his failure to satisfy gender norms; the ensuing feelings of shame and embarrassment might then lead him to withdraw from society, restricting agency by limiting his opportunities to engage in other activities without further jeopardizing respect. Tables 1 and 2 and the supporting literature suggest several pathways by which adverse psychological, psychosocial, and social impacts of these 2 diseases coexist and interact across dimensions to produce clusters of disadvantage.

DUTY TO AVERT AND ALLEVIATE CLUSTERS OF DISADVANTAGE

According to multiple converging theories of social justice, as registered in our core framework, lymphatic filariasis and onchocerciasis are each associated with precisely the categories (agency, association, and respect) and distributive pattern (clusters) of disadvantage that ought to be averted and alleviated as a duty and priority of justice. In general, disease control and elimination scenarios will feature greater long-term residual disease incidence than will eradication. Greater residual incidence is of ethical concern so far as it would impose correspondingly greater burdens of disease-related clusters of disadvantage in agency, association, and respect. Other things being equal, eradication of lymphatic filariasis and onchocerciasis offers the ethically superior prospect of more completely addressing the relevant duty of justice.

Things would not be equal if eradication strategies entailed adverse impacts on agency, association, or respect through actions or consequences not entailed by elimination or control strategies. For lymphatic filariasis and onchocerciasis, the most worrisome possibility involves affronts to agency, association, and respect through coercion.[93] For both diseases, eradication would require that mass drug administration reach certain levels of population coverage over several successive years in endemic areas to interrupt cycles of disease transmission permanently. This raises the concern that coercive measures might be used as a means to achieve the levels of coverage needed. Although processes of community engagement, individual informed consent, and ethical monitoring of program activities are important under all EIC scenarios, they may need to be undertaken with particular intensity under the eradication scenario to manage and minimize the risk of coercion.

Each EIC, under all scenarios, should fully delineate the risk of coercion in terms of the specific public health intervention strategies considered, the degrees of community and individual acceptance or resistance anticipated in all geographic locations critical to program success, and the likelihood that local community engagement efforts will be effective. All scenarios ought to identify all

available noncoercive measures and build in the assumption that they will be used in preference to coercion. No coercive measures should be adopted unless the principle of least restrictive means is scrupulously observed and the measures are otherwise ethically justifiable on grounds of both international human rights standards and multiple existing public health ethics frameworks.[20,21,94–96]

With respect to any residual occurrence of coercive measures, the extent to which eradication would require them more than would elimination and control would be a factor that counts against eradication from the standpoint of the core social justice framework; this is because of the adverse impacts of coercion on agency, association, and respect. In cases in which coercive measures would be necessary to achieve eradication, intrapersonal or interpersonal trade-offs between protecting agency, association, and respect (by limiting public health intervention) and more completely averting and alleviating clusters of disadvantage (by reducing long-term residual disease incidence) may be inevitable. Although our proposed method of ethical analysis in EICs would not in itself resolve such trade-offs, it would at least help people to identify, clarify, and deliberate about them.

Another relevant way eradication of lymphatic filariasis and onchocerciasis stand to differ from elimination and control is in projected costs and cost effectiveness. Typically, disease prevention exhibits diminishing returns and increasing marginal costs, but this may not be true of eradication because it would obviate long-term costs of disease prevention and treatment posteradication.[97] As seen with smallpox, eradication of lymphatic filariasis and onchocerciasis might be not merely cost-efficient but actually tremendously cost saving in virtue of averting all future cases and correlative future needs to expend resources on prevention and treatment.[97] If this bears out in projections for lymphatic filariasis and onchocerciasis, eradication would offer the ethically significant advantage of enabling more complete long-term joint satisfaction of duties of justice to address disadvantages linked to lymphatic filariasis and onchocerciasis and coexisting disadvantages linked to other noneradicable diseases or nondisease states of affairs.

It may also be, of course, that things are not equal across other aspects of comparison that make up a complete EIC. Any decision about how to spend limited resources must be comparative, and thus the overall warrant for eradication as compared with elimination or control must depend on numerous technical, pragmatic, political, and financial comparisons as well as ethical comparisons. We have simply illustrated how theories of social justice can be linked to empirical literature to guide comparative ethical analyses of the burdens, benefits, and distributions thereof that are not otherwise captured by traditional approaches to health and economic evaluation within the EIC framework.

CONCLUSIONS

The method of ethical analysis we have illustrated is adaptable for use not only in EICs but also in broader research, planning, deliberation, decision-making, and program implementation regarding eradicable infectious diseases. Attention to agency, respect, and association as dimensions of well-being that have fundamental ethical importance as a matter of justice, together with observance of the duty to avert and alleviate clusters of disadvantage, should guide future social science research on people's experience of these diseases. It should inform respectful deliberation and decision-making at international, national, and local levels among the diverse individuals and groups that stand to be involved in or affected by disease control, elimination, or eradication efforts. It should also inform the ethical monitoring of such efforts to ensure that ethically problematic actions and consequences are identified, mitigated, abated, and prevented from recurring. Finally, we also hope to have illustrated by example the potential for the core framework of social justice to meet similar needs for ethical analysis in relation to other kinds of health programs. ■

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