

Assessing Health Deprivation in India

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I. Introduction

Why are individuals unable to effectively access health care and to avoid disease in India? The answer to this question, of course, depends both on the particular form of illness and the regional and social context of the individuals involved. While understanding the biomedical reasons for the persistence of disease and ill-health are perhaps the most relevant in terms of treatment, socio-economic factors and infrastructural factors are well recognized as critical factors in the persistence and prevalence of ill-health as well. The latest WHO commission on the Social Determinants of Health (2008) suggests that addressing such issues may have as important an impact on reducing disease burdens as creating widespread access to medicine. What we hope to provide in this paper is a lens through which to address the relevance of these issues in the Indian context. In doing so we develop what may be termed a health deprivation framework and apply our template to a single disease as an example: Visceral Leishmeniasis (or Kala-Azar). The purpose of such an exercise is to help identify policy gaps and lacunae in understanding in the causes of ill health and/or the implementation of effective remedies. Thus, for example, does the identification and prevention of socioeconomic causes for disease take a back seat to devising treatment? And if so, what are the potential and implications of altering existing approaches? Our approach is motivated by the work of the committee on the Social Determinants of Health at the WHO (2008), but differs in devising an explicit framework through which to assess health. In doing so, we draw upon the work of health access deprivation by Phillips and Bazemore (2006).

At the outset, it is useful to reiterate that health is more than simply the absence of disease. As the WHO has maintained for over 50 years now, it is to be defined as a state of complete physical, mental, and social well-being. Such a definition is useful to distinguish between public interventions which solely reduce the disease burden or morbidity, and those which reduce disease and also restore the affected individuals to a state of health. A variety of clinical interventions can lead to temporary reductions in disease or lead to severe side effects which reduce compliance, or for socioeconomic and infrastructural issues to prevent the eradication of a deadly disease. These processes are readily seen in the case of visceral leishmaniasis (Carvalho and Ferreira, 2001). Despite the significant efforts to develop new drugs, in several parts of the world there are few universally viable therapies. All those that are currently used (liposomal/amphotericin B, antimonials (sodium stibogluconate or SSG/gluconate), miltefosine, and paromomycin) have serious limitations in terms of pricing, safety, drug resistance, toxicity and so on¹. Furthermore, the disease has tended to affect a relatively poor, uneducated rural population with significant vulnerabilities in terms of their ecological environment and economic position. Given the presence and persistence of the disease, it is particularly important to understand which constraints to achieving health are the most relevant and therefore require the most urgent attention (see Desjeux, 2004).

We may conceptually divide these constraints very broadly into two types: the individual/social and the infrastructural/ecological. Among the former concerns are such issues as whether the disease is primarily rural or urban, whether it affects people at various scales of income differently, whether it affects particular caste groups, whether women or men are more affected by it, whether it has a social stigma attached to it and so on. The latter concerns by contrast include the ease of access to health care centers, the types and viability of available therapies, the infrastructural support to make healthcare affordable (insurance schemes and so on), whether the individual lives in an area with clean water and adequate housing and so on. In other contexts this distinction has been referred to as the distinction between individual and ecologic variables. One of the

¹ It should be noted that the current trials of Ambisone, being conducted by the MSF in Vaishali district of Bihar shows greater efficacy than current therapies, but is also considerable more expensive.

purposes of attempting to provide an integrated framework to identify the reasons for these health gaps is to identify areas in which information is missing and thereby indicate to concerned researchers and policy makers areas in which further in-depth studies and collation of existing studies are required. By focusing on socioeconomic factors and the ways in which these might interact with other factors to influence health, we hope to stimulate more research into such topics—a set of considerations which have thus far been relatively neglected. In attempting to understand the types of health impacts and their effects, we suggest the need to identify alternative and broader indicators of health than morbidity rates (including disease concentration among communities, the influence of ill-health on households, cultural differences in the perception of what constitutes good health and so on).). Such an integrated framework will allow us to go beyond universal quality of life indicators creating the possibility for community specific definitions of good health. With the rapid increase in the diagnosis of “life-style diseases” such as diabetes, cardio-vascular etc. such a definition has become even more important in order to prioritize resource allocations. Distinguishing between health indicators that are universally valid and those that can culturally differ may be one of the outcomes of this framework. It will help us make the choice between say providing subsidized statin therapy versus nutrition for cardiovascular treatment in some communities.

II. A systemic framework for understanding health deprivation.

As noted in the introduction, the current health literature has attempted to classify reasons for uneven access to health care as arising from individual variables and structural variables. An important framework in which to study the way in which these two interact to systematically determine the manner in which individuals are discouraged or prevented from obtaining health is provide by what is known as the access deprivation framework (Phillips and Bazemore. 2006). Such a framework can be expanded in scope to develop what may be termed a health deprivation framework, in which the systemic constituent factors which prevent the achievement of good health can be identified. If public health is

to be seen as a critical public good, it is important to identify the ways in which to promote it with the different tools available to policy makers. . It is important to note that people from all segments of society may feel deprived of “good health”.

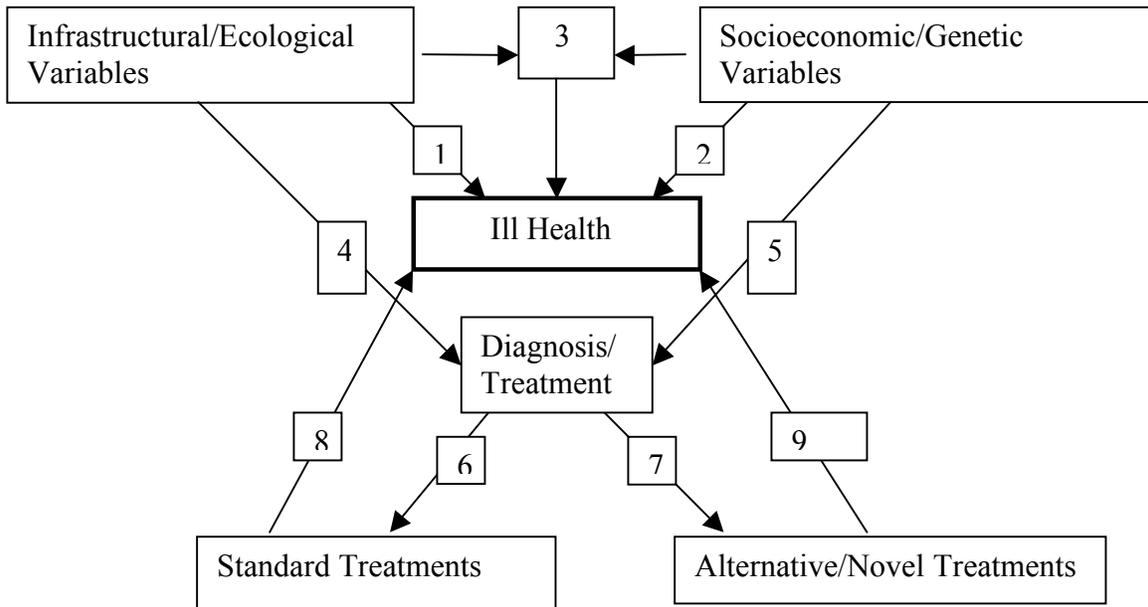


Figure 1 above is a very simple schematic representation of such a systemic framework. If one is to think of the purpose of health systems as being to reduce ill health, policy makers need to understand the intricacies of several broad relationships.

A critical set of relationships that need to be considered is the interactions between the deeper socioeconomic/genetic and infrastructural factors which create the conditions for ill-health. Thus for example, poverty and unemployment affect the location and quality of housing and also contributes to a lack of adequate nutrition. Similarly, ecological factors (land quality, environmental surroundings) and infrastructural bottlenecks (public sanitation, ease of access to primary health care etc.) affect the ability of individuals living in that locality to break out of a cycle of poverty. This interaction can produce the conditions for ill-health in combination (pathway 3), or each factor can have distinct impact (pathways 1 and 2). For example, respiratory illnesses may depend more on

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infrastructural factors (high levels of pollution) than on socioeconomic factors.

Conversely socioeconomic causes are the most important factors in the persistence of malnutrition related diseases such as marasmus and cretinism and sociocultural practices (for example the foraging of animals) can expose individuals to particular diseases.

Furthermore, such factors also determine the very nature of the understanding of what constitutes health. Recent research suggests the importance of cultural understandings of health and how such understandings relate to accepted types of treatment. Thus for example, mental health is clearly seen to be culturally specific and is this related to in very distinct ways. Often the legitimacy of treatment often needs to be established by external authorities.

Socioeconomic and Infrastructural factors are as important in determining whether treatment for ill-health is obtained (pathways 4 and 5), and if so, which sorts of treatments (standard or alternative) are obtained (pathways 6 and 7). A lack of knowledge of the disease due to a limited education, or the worry of social stigma for some diseases, or most simply, the lack of adequate resources can serve to deter an individual from accessing healthcare at a primary health center. Equally, a lack of adequately staffed health care centers and geographic distance from such a center can act as a deterrent to choosing such a path. Instead of a standard treatment then, the individual may choose to pursue alternative therapies, which may range from out and out quacks to more broadly 'acceptable' therapies such as yoga, ayurveda, unaani or homeopathy, or indeed, new therapies which may turn out to replace the standard therapies (vaccines, new chemical entities and so on)

The choice of treatment in turn has an effect on ill health. A priori, these treatments could serve to either ameliorate or worsen the ill-health burden. One can imagine, for example, that a standard drug treatment could reduce or eliminate disease. On the other hand, indiscriminate use could serve to create severe resistance which might in the medium term increase the disease burden. Among alternative therapies, one can imagine that treatments could serve to be ineffective at best and dangerous at worst (by prolonging the

disease till it becomes difficult to treat and spreads amongst the community). Equally, one can imagine that they afford non-invasive ways in which to control or reduce other symptoms (for example, reducing asthma attacks or hypertension through breathing exercises).

Policy makers seeking to reduce the prevalence of ill-health can focus on prevention (pathways 1-3) and/or treatment (pathways 4-9). Typically, given limited resources, more effort is placed on one or the other set of concerns. The key issue for policy makers is to be able to target resources appropriately between prevention, diagnosis/treatment, maintenance of good health. We believe that this integrated framework will help prioritize such resources and more importantly make sure that adequate resources arrive at the right time in order to create good health. This means quick cure, maintenance of cure, and lack of complications setting in the future (resistance, toxicity effects, co-infection, re-infection etc.).

We now turn to a specific case (the proposal to eliminate Visceral Leishmaniasis by 2010) as a study to illustrate the use of this framework.

III. Visceral Leishmaniasis: A Review of the Literature and Field Experience.

Background:

There has been a substantial amount of research done on the causes of visceral leishmaniasis (VL). It is a long existing parasitic disease caused by *Leishmania donovani* and transmitted by the bite of the sand fly vector *Phlebotomus argentipes*. India is host to a very large number of cases annually (ranging from 25,000 to 40,000 cases with about 200-300 deaths) and these are concentrated in the north eastern state of Bihar which accounts for more than 90% of the reported cases. Estimates suggest that VL results in a loss of about 400,000 DALY's annually (Joshi et al 2008, WHO, 2007), although this is certainly an underestimate given the number of undiagnosed cases. Anecdotal evidence collected from researchers at the Rajendra Medical Research Institute (located at Patna,

Bihar), suggest that the number of unreported cases might outnumber the number of reported cases by three to one. A recent study (Joshi et al 2008) which undertook a sampling study of endemic regions suggested that the current disease burden was in the range of 21 per 10,000 population, or about twenty times that required by the target of elimination. Furthermore, late diagnosis continues to be a problem and an increasing number of post kala-azar dermal leishmaniasis (PKDL) cases as well as asymptomatic cases and subclinical cases have been identified. The study found significant delays to treatment, with more than 20 percent of their sample reporting a greater than three week lag between symptoms and diagnosis and an equal lag between diagnosis and treatment for over 30 percent of their study sample. These facts in turn contribute to the persistence of the disease among the population and more expensive treatment. Given these factors the stated aim of the Indian government--to eliminate VL by 2010--looks almost impossible to achieve.

Given that the disease has been studied for decades, researchers have identified several contributing factors to the persistence of the disease. For the most part, the biomedical approach has focused on identifying viable treatments to the disease, while the public health perspective has sought out preventative options. In terms of the systemic approach therefore, there has been substantial focus on the pathway (3), and some focus on pathway (1) as well as on treatment options (pathways 8-10) and various programmes have been undertaken to limit the spread and impact of the disease. We summarize these as below:

Infrastructural and Ecological Factors determining Illness and Treatment (Pathway 1 and 5)

It is now well recognized that the sand fly vector has particularly propitious conditions to breed in the Bihar region. The riverine plains of Bihar with its high subsoil water tables, the abundance of alluvial soil and seasonal floods are important conditions for their breeding. In addition, a major factor which allows the spread of the disease to human hosts is the use of mud and mud plastered walls in rural human or livestock habitations,

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which is a common practice. These walls cool housing structures, but also retain moisture, which allows the sand-fly to breed and to infect nearby hosts. Furthermore, the presence of certain types of vegetation has also been seen to increase the prevalence of the disease. Given these conditions, a number of programs and remedies have been suggested. It has been, for a considerable period of time accepted public health protocol in Bihar to spray houses with DDT to kill sand flies. In fact, the reduction in VL cases in the 1980s and 1990s was seen to be the collateral benefit of DDT spraying in the area for malaria vector control and sand fly resurgence occurred following the cessation of that program. As an alternative, malathion paint, a slow-release emulsified suspension has also been shown to be effective in the purpose. Current trials with combinations of these and other chemicals are being undertaken. In addition, creating lime and mud plastering to cover crevices has been promoted as a more ecologically sustainable way of limiting sand fly growth. More radical suggestions, such as the Indira Awas program seeks to expand an ambitious public housing project to service the most vulnerable populations and to do away with the mud plastering altogether. Such a program would also limit secondary health hazards arising from other infrastructural vulnerabilities such as poor sanitation.

As part of the general IRS programs, mosquito nets and mosquito protection have been promoted. This has been shown to be very effective in certain pilot studies (references), and various small to medium scale operations to promote their use have been undertaken. Thus for example, apart from public service announcements, Medecins Sans Frontiers provide two mosquito nets free to any person coming to their Vaishali district headquarters with confirmed VL.

Another set of critical infrastructural issues have to do with the ease of access to a functioning primary healthcare center. While the state has over 300 primary healthcare centers, it is not clear whether they are easily accessible given the conditions of the transport system. Furthermore, even if they are accessible, the centers are often understaffed or unstaffed, as doctors supplement their public sector income with private income. In some cases doctors have not even received regular salaries for a number of

months and usually have to run two households at the same time. Drug supplies are often inadequate and an unambiguous protocol of dealing with the disease is lacking which means that drug resistance has been on the rise. In the most functional primary health care centers (for example as in Mahua PHC in Vaishali district, doctors follow a protocol devised by MSF to diagnose (using the RK 39 kit)² and treat (using Ambisone, or referring patients to the MSF headquarters for Ambisone). They are nevertheless unable to adequately diagnose cases with co-infections. In other districts, there is a mixture of diagnosing protocols and drug regimes (Miltefosine or Sodium Stibogluconate or SSG/Gluconate) which have different and more taxing side effects. New programs to motivate doctors and to ensure some accountability through private-public partnerships in healthcare delivery have been established.

Socioeconomic Factors determining Illness and Treatment (pathway 2 and 6)

Socioeconomic factors are by far the least well understood component of the systemic viewpoint. A lack of rigorous data collection and the relatively low weight given to the primacy of social and economic underpinnings of disease has meant that researchers have relied on small sample surveys at best and impressionistic evidence for the most part to conduct their analyses. Partly as a result of this, VL has been seen as primarily a biomedical issue and there has been little concerted effort (until recently) to interface with poverty focused programmes. Some socioeconomic factors underlying the disease however are reasonably well established.

VL is a disease which primarily affects the rural poor. The inability to secure reasonable protection against the disease is strongly linked to extreme poverty. Moreover, the fact that economic vulnerability is extremely high among communities in which VL is prevalent means that diagnosis is often delayed because affected individuals need to work to maintain a family's survival. VL further pushes families into poverty by increasing debts. The cost of obtaining drugs from a private practitioner (before the current free

² Note however that RK39 is an initial diagnosis kit. Therapy is provided only after this is confirmed clinically through physical examination. All this further delays the start of treatment.

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supply of drugs provided by the government and donors) was a significant deterrent to obtaining treatment. Finally, lack of knowledge as to the causes of VL and preventive steps that can be taken are also related to a lack of literacy skills. An important program that has been undertaken by the Bihar government seeks to compensate a VL patient Rs. 50 per day as lost daily wages in addition to providing free food to an attendant. Initial evidence suggests that this policy has significantly increased inflows into the primary healthcare system (i.e. it has reduced dependence on alternative treatments and increased usage of standardized government health care (pathways 7 and 8). However, it is as yet too early to know whether this has reduced the disease burden directly or indirectly through reducing the lags to treatment for example (pathways 9 and 10).

In Bihar, anecdotal evidence suggests that VL is most prevalent among a particular caste group-the Musahars ((musa-rat and ahar-diet)-a landless community who are often exploited them as bonded labourers or as day laborers in cleaning fields of rodents. This view however could easily be a myopic generalization by which a stigmatized community is seen as a carrier of a dreaded disease. There is no systematic evidence for this belief.

Another suspected, but not confirmed hypothesis is that the growing number of co-infections in VL cases has to do with the large scale migration that occurs in the state. The latter patterns are due to the widespread economic stagnation and the possibility of better opportunities in growth centers such as Delhi, Punjab, and even cities in the South. HIV co-infections in particular have been on the rise in Bihar. An increase in VL cases in other states (most notably in Delhi) has also been seen, possibly due to migration. The difficulties in managing a disease become far more complex when the carriers of the disease migrate between locations. As of yet, this has been seen to be a negligible threat, though precisely such a concern has been mentioned in trilateral meetings between Nepal, Bangladesh and India.

Socioeconomic and Infrastructural Factors in Combination (pathway 3 and 4)

For the most part, policy makers have focused on vector control through IRS and spraying programmes and on finding viable first and second line therapies. Anecdotal evidence, however suggests the importance of incorporating socioeconomic factors before the implementation of such programs given the interaction between infrastructural and socioeconomic considerations in society. Thus, for example, there is widespread concern that because of poverty, the primarily agrarian livelihoods and the prevalence and acceptance of mud housing, DDT spraying is less effective than it might be. Given its use as a pesticide, anecdotal evidence suggests that some of the stocks of DDT are diverted to crops and to protecting farm animals. Equivalently, mosquito net programs are diverted to farm animals, or are used sparingly since cots are not prevalent and several family members sleep outside the house (where sandflies are still abundant). Equally, there is concern that even with better houses, mud plastering as a cooling device might still be used. While perhaps marginal, these concerns suggest the need to undertake a concerted systemic viewpoint in implementation to ensure the maximal impact.

IV. An Institutional Mapping of VL Control and Treatment

Although all institutions involved in the control and treatment of ill-health engage in multiple functions and objectives, their prime directives may be different. These may be categorized as follows:

1. Generation of basic knowledge (national and international public and private sector social and scientific research institutions and education and training institutes)
2. Policy and standards setting organizations (MoHFW, ICMR, DBT, IMA, WHO)
3. Policy and standards influencers (NGOs, think tanks, industry, key opinion leaders including politicians, media)

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4. Task forces, national programmes and oversight groups such as Rural Health, Vector borne diseases etc.
5. Funding agencies (government, trusts, international bodies-private and government)
6. Implementing agencies (Central and State government departments, local government and communities, semi-formal sector such as ASHA workers, public-private partnerships, NGOs, international project workers such as world bank, DFID etc.)
7. Monitoring and control units and overall accountability (Central and State government, media, key opinion leaders including politicians, NGOs etc.)
8. Information infrastructure for policy development and implementation (Census, NSS,

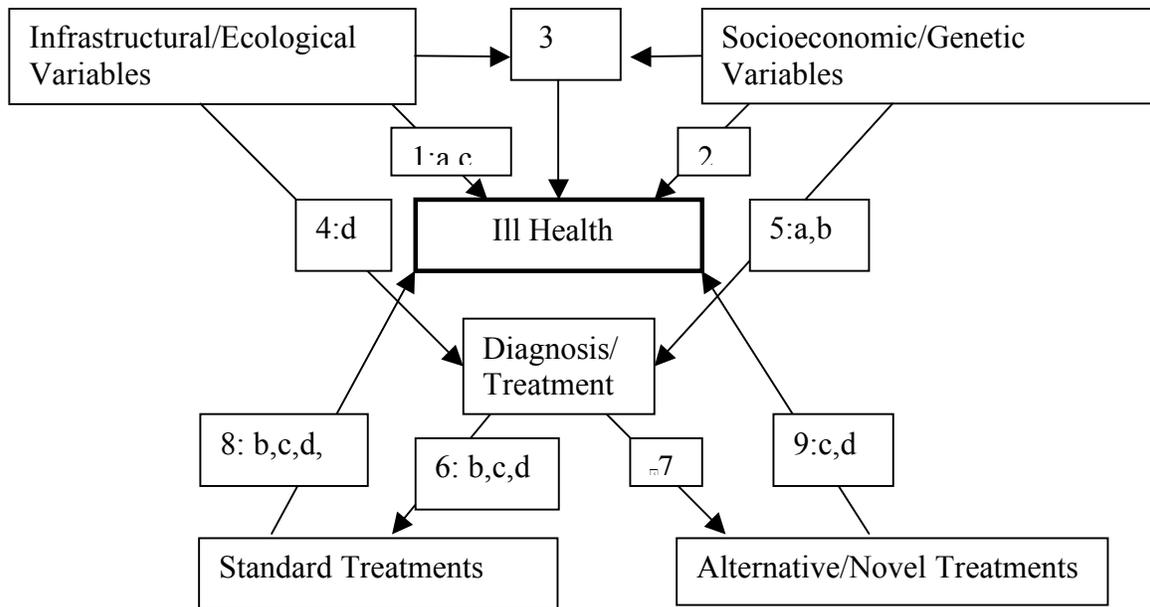
The overall purpose of all these institutions is to ensure that all the “pathways” identified in figure 1 work towards the reduction of “ill health” in the short and long term. And this is to be done in a holistic way that ensures that a reduction in a disease burden in the short term does not end up increasing the “ill health” burden in the long term.

1. Basic Knowledge generation is done by national and international research institutes working on *leishmania* . In particular, RMRI in Patna covers a lot of the basic knowledge generation specific to VL in Bihar such as:
 - a. Sandfly behaviour and control studies
 - b. Efficacy of pesticides (DDT, malathione)
 - c. Co-development of new pesticides
 - d. Basic research on parasite (genetics)
 - e. Testing of oral diagnostics (using RK39)
 - f. Development of new diagnostics
 - g. Study of drug resistance
 - h. Clinical trials on combination therapy to combat resistance and reduce costs

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- i. Study of co-infection (HIV, TB)
 - j. Research on PKDL
 - k. Some socio-economic studies
2. Policy and standards are set for treatment by the National Vector Borne disease Program but modified to suit constraints of resources by the government of Bihar. Some politicians/key opinion leaders are influencing decisions such as combination therapy, housing and pesticide spraying. *Medicines Sans Frontieres* is an NGO which is also influencing the treatment standards
3. The National Vector Borne disease programme is influencing the direction of activities
4. Most implementation is being done by the Health department of the government of Bihar incorporating larger principles unique to Bihar such as public-private partnerships etc.
5. The NGO *medicines sans frontieres* plays a very important role in establishing alternative treatment practice and supply of nets etc.

In what follows, Figure 1b specifies the use of the framework for Kala Azar in Bihar. A number of institutions play a role in influencing the different pathways in figure 1. Figure 1b- drawing on figure 1- maps out how some existing organizations are attempting to influence and reduce the disease burden. For each pathway the diagram shows the presence of the different organizations mentioned above. Each letter refers to a specific organization or set of organizations as follows: a) Bihar Government Programs, b) Bihar Primary Health Care Centers, c) Rajendra Medical Research Institute and d) NGOs such as *Medicins Sans Frontieres*.



Key: a: Bihar Government Programs, b: Bihar Primary Health Care Centers, c: Rajendra Medical Research Institute, d) NGOs (MSF)

The Bihar Government as might be expected has a role in trying to limit the infrastructural and ecological causes for VL. As such, programs such as Indira Awas and DDT spraying which attempt to control the sandfly vector try to minimize the impact of infrastructural and ecological vulnerabilities on the spread of the disease. Interestingly, there are also attempts centered at the RMRI which is trying to think of different inhibitors of the vector other than DDT, such as Malathion Paint. As such, organizations (a) and (c) are involved in pathway 1. There is very little direct knowledge of and operations in pathways 2 and 3 as noted before. This is a serious issue which merits discussion. It is also important to note that the Bihar government does not appear to address directly the issues associated with the infrastructural bottlenecks associated with obtaining treatment (pathway 4). Thus, for example, we found evidence that only Medecins Sans Frontiers (organization c) directly attempts to take treatment to the patient (through mobile diagnostic camps and the like). The government has ceased active searching for the disease. The Bihar government and primary health care centers are,

however involved in pathway 5. The new program which compensates anyone with a diagnosis of VL from a PHC with lost wages of Rs. 50 per diem targets the socioeconomic causes for delay of treatment. Further, this limits the use of some alternative treatments. As noted above primary health care centers, MSF as well as RMRI all play a role in providing a standard set of treatments. The relative importance of each institution depends on the type of case and the geographical location of the patient. Thus, pathways 6 and 8 have the most well established organizational involvement, with a clear rationalization of the role of each actor. There is no direct mechanism by which alternative or novel treatments are being demanded or sought (pathway 7). Thus for example, there is no organization yet which is attempting to procure cases for a new clinical trial or similar activity. However, there are new and novel therapies which have been promoted by the RMRI (combination drugs) and MSF (Ambisone) as noted by the organizations involved in pathway 9.

V.. Insights from Framework and Further Research

This framework was developed to generate a more holistic approach for providing policy suggestions in health and to offer a different perspective on understanding the limitations of current policies. As a general framework, this paper has only sketched out a set of relationships which should be looked at in combination if one is to answer and remedy the original question posed (who are individuals unable to effectively access care and avoid disease). For any more detailed study, therefore some additional steps may be taken to implement this framework as applied to specific diseases, health conditions and health related events. These would include:

1. Review of the literature to clearly delineate elements in each box
2. Summarize the literature in terms of creating a narrative on each of the pathways
3. Identify information gaps and data gaps

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4. Identify alternative views on standard treatments, novel treatments, and alternative treatments
5. Review of studies on impact analysis in order to put them into the different elements of the framework
6. Develop “on the ground” methodologies to elicit information on outcomes from those directly affected and healthcare workers on the ground
7. Develop methodologies to elicit outcome information and process efficiency information from NGOs and media reports
8. Analyze the data generated in order to develop a critique and/or a new set of priorities for resource allocation

This said, the preliminary application of the framework to the case of VL has established some important gaps and inconsistencies in the management of the disease. From figure 1 b, what is immediately apparent is that the major gaps arise in our understanding of socioeconomic causes of the disease. Nor is this situation likely to be remedied any time soon. The National Sample Survey on health does not have module on Kala Azar and very few high quality systematic surveys are done. There is additionally very little information about the patients gathered at the primary health care level, and thus little is known about household characteristics and responses to disease. We are unaware further about the impacts that social processes such as migration have on the persistence and transmission of the disease, and no information about compliance with current drugs. Gaps also exist in the availability of treatment for remote individuals and families. Finally, while the protocol for treatment is being rationalized, it is not standardized and there is little clear information about the costs and benefits of each line of treatment.

All of these lacunae point to the notion that the set of policies in place currently may be suboptimal. It is entirely conceivable for example that a scaling up of anti-poverty measures which act directly on the socioeconomic causes of disease will have a much more powerful effect on reducing the disease burden than the myriad efforts at infrastructural and ecological controls that are being tried. Coordination of research

and policy efforts by various actors who are dealing with one or the other aspect of the disease may have significant benefits. Until a more comprehensive view of the maintenance of health is considered (and to which our analysis points), policy makers will, despite their best efforts be flailing in the dark against a devastating and tragic disease.

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