

# LEISHMANIASIS CONTROL STRATEGIES

A CRITICAL EVALUATION OF  
IDRC-SUPPORTED RESEARCH

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# Leishmaniasis control strategies

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# **Leishmaniasis control strategies: A critical evaluation of IDRC-supported research**

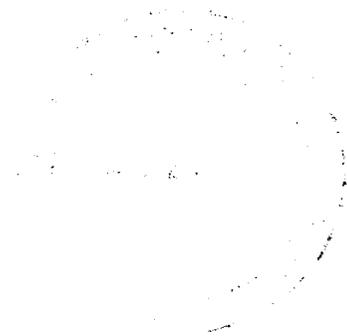
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# Creating and Sharing Knowledge for Action: Towards a New Way of Seeing the Problem of Endemic Diseases

Christina H. Zarowsky<sup>1</sup>

I was going to call this paper "Can Anthropology, Ecology, Immunology, Political Science and Epidemiology Fit in One Useful Sentence?", but I discovered that they barely fit on the same page. Instead I decided to use my position as both a physician and a representative of a research funding agency to offer a critique of physicians and funding agencies. I would like to challenge a prevailing view of science as a neutral, objective enterprise of cooperation among equals from various research disciplines. The hope is that this will encourage us to rethink the way we see the problem of endemic diseases, so that research from different disciplines can be more effectively shared and coordinated.

I would like to start with a quote from a paper by Dona Lee Davis (1986 quoted with permission of the author), a North American anthropologist studying health conditions among North American women. In this case the condition is menopause, and the women are residents of a fishing village in Newfoundland, Canada's easternmost province. There is no link to leishmaniasis. However, as the author indicates in her paper, this vignette illustrates several of the issues we will be grappling with over the next few days, such as:

- the difficulty of communicating across cultural barriers, whether barriers of language, gender or occupation;
- the tension between wanting to quantify things that are difficult to measure (in this case, how women perceive menopause), and the need to acknowledge and explore their complexity.

The following exchange is between the researcher, trying to administer a questionnaire designed to be both quantitative and cross-culturally valid, and one respondent. It covers a single question ("R" refers to the researcher; "W" refers to the Harbour woman being interviewed).

*R: To what extent do you have worries and problems about your work about the house? Are you: 1. especially worried, 2. quite worried, 3. not so worried, 4. almost not at all worried, or 0. not relevant.*

*W: Which do you mean, dear? Worry or problems? You can have one without the other, you know. Mabel over in Crow Cove...*

*R: This is about you. (Repeat question and answer items 1 - 4, 0).*

*W: Well, my dear, why you ask that is beyond me, but I do tells you,*

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*I do worry some awful. To tell the truth, I worry more than most, always have.... [I] got it from my own mother, her nerves, you see....*

R: *What about worry over your work in the house?*

W: *Tell me again what I'm supposed to say?*

R: *(Repeat question and answer items 1 - 4, 0).*

...

W: *What's the difference between "quite" and "not so" worried?*

R: *The quite means you're more worried than the "almost not at all" does.*

W: *That's not how we mean it, my dear. I'd say "quite" was the four, not the "almost not at all".*

R: *That's not the question. Here, "quite" means more than "not at all". Do you worry about housework, now?*

W: *No, I shan't be so silly as to get all worked up over that. Give me a naught. That's how we say zero.*

R: *That means it's not relevant.*

...

W: *I find doing the dishes four times a day [to be] a bother.*

R: *I think worry here is supposed to mean stress or anxiety.*

W: *What?*

R: *Like, does it get on your nerves?*

W: *Well then, dear, you understand it better than I. You check what you sees fit.*

R: *You tell me what you think first.*

W: *Either you worry or you don't. Some days, it grates on my nerves. Some days it doesn't.*

R: *Housework?*

W: *No, that'd be foolish, unless mother's trying to help and its spring cleaning time. I worries that she's too old, but you can't hold her back. Poor dear's had one hard life.*

R: *(Repeat question and answer items 1 - 4, 0).*

W: *What did Betty tell you on this one?*

R: *This one's for you. I need your answer.*

W: *It's hard to say. I want to do well on this test, but I must be some stunned, because I'd never thought about it like this.*

R: *It's not a test. In this case, you're the expert. You have all the right answers. I'm just here to learn from you.*

W: *Well, my dear, if that's how you see it. I'll take the five.*

R: *There's no five. (Repeat question and answer items 1 - 4, 0).*

W: *O.K. It's probably a lie, but I'll take the four.*

R: *Thanks. Ready for the next question?*

Such an interaction is not uncommon, although the degree to which the interviewer tolerated questions may be unusual. In the "Results" section of a typical

publication arising from such an interview, however, all information would be lost except that the answer was "Four". Depending on who is asking what kinds of questions, what is important in this interchange could vary from the ultimate answer ("Four"), to the nature of the relationship between interviewer and interviewee, to what the discussion itself indicates about the respondent's feelings about housework. Each of these is a valid question; what I wish to convey here is that the process of asking and answering questions in any research, including medical research, is complex, and that decisions about what questions to ask or which projects fund are not neutral.

Multidisciplinary research is in vogue. The apparent consensus is that tropical diseases, indeed most health conditions, are multifactorial and must be addressed in an integrated way with respect to both research and control strategies.

So, how does this work in practice? *Is* there much inter- or transdisciplinary research? I would argue that there are indeed multiple disciplines involved, but that they are largely working in parallel. The problems and questions considered interesting or important, the methodological approaches considered valid, and the definition of the object of research, are those of the particular discipline of the researcher. They are also partially determined by the history of research on a given subject and the availability of funding.

That there are major -- at times it would seem, irreconcilable -- differences in the theoretical frameworks that guide various research agendas, from the selection and formulation of research questions to the analysis and utilization of data, is no surprise to most social scientists. However, natural scientists in general and biomedical researchers in particular often seem blissfully ignorant of the existence of other, equally valid ways of understanding reality; they seem genuinely unaware of the idea that *their* work is *also* shaped in its every aspect by often implicit assumptions.

This can be critically important when undertaking multidisciplinary research in health, because the combination of the point of view that biomedicine is just studying "objective reality", the political and economic power held by physicians, and the urgency to *do something* that physicians develop almost as a reflex makes it very difficult for other voices to be heard. As a consequence, the questions, priorities and conceptual frameworks brought to bear on the problem of ill health related to endemic diseases are usually determined by biomedicine; "multidisciplinary research" often becomes no more than the piecemeal addition of techniques developed by other disciplines. For example, there has been a good deal of research on schistosomiasis in Mali, but it has *not* been focused on the fact that bilharzia was not endemic to Mali until certain irrigation projects were undertaken (U. Brinkman, personal communication). Thus, research questions that would be of major interest to social scientists, such as the reasons for, nature of, and impact on local populations of so-called development projects are not asked, and social scientists are invited to suggest good ways of persuading the local people to use latrines.

That multidisciplinary research can be much more than this is beautifully shown by some of the papers to be presented at this meeting. Biomedical and social science researchers and the funding agencies involved in endemic disease research need to take an objective step back, look at our assumptions and their implications, and begin in earnest a dynamic, iterative process of narrow focus and analysis, the hallmarks and source of power of the natural sciences, with synthesis and an examination of what happens at other levels and interfaces of reality.

In moving towards cooperation with other researchers and away from cooptation:

***Step One on the road to creating and sharing knowledge for action is: overcome M.D.-centrism and acknowledge that it is not just the others who have a theoretical framework.***

What is the nature of the theoretical framework guiding biomedical research in endemic diseases? There have been literally volumes written on this question, and the answer is far from being agreed upon. However, the particular aspect that I would like to draw attention to is the prevailing view held by many scientists and large segments of the population: that science is "true", that it is objective and value-free, that the role of the scientist is to discover and document, from a position of objectivity and neutrality, the reality that is "out there". Some corollaries of this are that scientific work is guided by rational choices having to do only with the scientific questions under study, and that it is not really the scientist's responsibility to "use" the knowledge he or she gains.

A different view, whose best known proponent is perhaps Thomas Kuhn through his book "The Structure of Scientific Revolutions", sees sciences as a human endeavour, and therefore inevitably social, cultural, economic and political. Such a view helps to explain some of the apparent "inconsistencies" to be found at every turn.

By way of example, Judith Justice's anthropological studies of primary health care bureaucracies found, among other things, that countries adapted their existing health care structures and manipulated the identity and terminology of programs in order to accommodate the new international directive of primary health care. Rather than encouraging creative, research-based approaches that responded to their own needs, ministries of health re-named erstwhile malaria workers as "village health volunteers". This is perhaps "unscientific", but it is hardly surprising, in Justice's view, given the way that new strategies are promoted by international agencies. A country such as Nepal, about half of whose budget comes from foreign aid, can hardly do otherwise in a setting where, as Justice writes in 1987, "within a decade international policy shifted from

vertical approaches to integrated basic health to community participation to P.H.C.", then back to vertical programs of diarrhoeal disease control and immunization, which formed the core of the "child survival" policy. In 1987, there were indications that the child survival policy was already being challenged by yet another new priority: "safe motherhood" (Justice 1986 & 1987). Funding agencies need to see their respective "priorities" in a historical, political and cultural context, rather than as the ultimate, obvious and scientifically proven "truth".

Uriel Kitron wrote a paper for the 1988 Takemi Symposium, published in "Towards International Co-operation in Health" (Reich and Marui 1989). He discusses an "integrated disease management" approach to tropical diseases, using as a model the "Integrated Pest Management" approach familiar to agricultural and ecological researchers. In analyzing successful and unsuccessful programmes addressing malaria and schistosomiasis, he and Spielman developed a semi-qualitative chart of the relative amounts of various kinds of resources needed for different types of disease management strategies. For example, strategies based on drugs and vaccines need a high level of external resources and at least district or even national levels of structural organization. On the other hand, small scale source reduction depends on community participation, local research, and local maintenance, but is independent of major external funding and only requires organization at the community level. It would seem "rational", given current and foreseeable economic and structural realities, to focus attention on those control strategies least dependent on lots of money and sophisticated organization, but this has not typically been the focus: the "interesting" research questions, especially if you want to advance your career, are at the vaccine and drug end of the spectrum. This, of course, reflects what biomedical researchers are trained in and where the money is: for the researchers, certainly, but perhaps more importantly, for the pharmaceutical and other companies involved. While developing countries may not be an attractive market for expensive drugs and vaccines, the countries producing the research are such a market. The WHO is also not an insignificant purchaser of drugs. That such considerations guide research choices is understandable if science is seen as a human and therefore cultural and political activity, but as long as the implicit and explicit assumption is of objectivity and neutrality, we can only continue to plug away at "interesting questions", provided that donors also think they are interesting.

A historical perspective is essential in order to understand the conceptual frameworks currently guiding both medical and social scientists. A discussion of the history of tropical diseases research and of the historical relationships between medicine, public health and anthropology is beyond the scope of this paper, but colonialism has played a decisive role in each of these fields. In the case of anthropology, the association of ethnographers with the strategic aims of the colonial powers has left both anthropologists and former colonies with bitter legacies. In some countries, such as Senegal, social sciences faculties were closed at independence. The apparent extreme reluctance of anthropologists to do anything that might seem to manipulate local populations on behalf of what might be interpreted as new colonizers -- economic,

political and scientific -- can be seen to stem at least in part from this colonial legacy. On the other hand, the very existence of tropical disease research *per se* in rich countries can be attributed, again at least in part, to this same colonial and military heritage.

Multidisciplinary research seems much less problematic in other fields; oceanography in the 1970's provides an excellent example of researchers from diverse backgrounds working together to understand the sea. One major difference between oceanography and endemic disease research is the absence in the former case of a strong normative element to "save lives and stamp out disease", whose "protector" in turn also happened to be the participating discipline with the most economic and political clout. Again, as long as biomedical research is seen as "value-free", this very real factor cannot even be legitimately discussed, let alone resolved. Discussion is limited to innuendo and grumbling, or explicit critiques to audiences of other "believers" at social science conferences.

In the introduction to "La construction des sciences", a text on the philosophy of science, Gérard Fourez explains that philosophy is a specialized branch of knowledge with its own history, tools, and methods of analysis, and just as it would be absurd to claim to know advanced mathematics without studying calculus, or to understand physics or chemistry without learning their basic concepts, so is it impossible to understand philosophy without studying *its* concepts and methodologies. He adds that it seems silly to have to point this out, except that natural scientists seem to lose all concern with scientific rigour the minute they step out of their own disciplinary boundaries (Fourez 1988). Biomedical researchers need to acknowledge that science itself is ultimately based on philosophical tenets, and to be aware of what some of these tenets are. It follows:

***Step Two on the road to creating and sharing knowledge for action is: move away from narrow unidisciplinarity and recognize that different disciplines have strengths and weaknesses, and that your own does not have a monopoly on rigour.***

George Foster is a senior professor of anthropology at the University of California at Berkeley. He has a long and distinguished career which has included frequent consultation for the WHO. In 1987, he published a rather blunt but hopefully constructive account of the frustrations of doing behavioural and social science research in the WHO. The main problem, as he saw it, was that doctors think that, by virtue of their training and experience as physicians, they are also qualified and capable of evaluating and doing first class social science research (Foster 1987). While Step Two is applicable to all disciplines, given the previous discussion of agenda-setting and power it is particularly directed at my biomedical colleagues, who are exhorted to repeat it out loud several times a day.

A truism of social sciences is that human beings are *by definition* social; Bonilla Castro and her co-authors write in "Salud y desarrollo - Aspectos socioeconómicos de la malaria en Colombia" that "the social is above all the essence of human nature, and not just a condition of life" (Bonilla Castro et al. 1991). Such a perspective allows, at least in principle, a narrowing of the artificial chasm between the "social or cultural" and the "biological" (or implicitly "real"), and sets the groundwork for a truly integrated approach to understanding health and the human condition in its entirety.

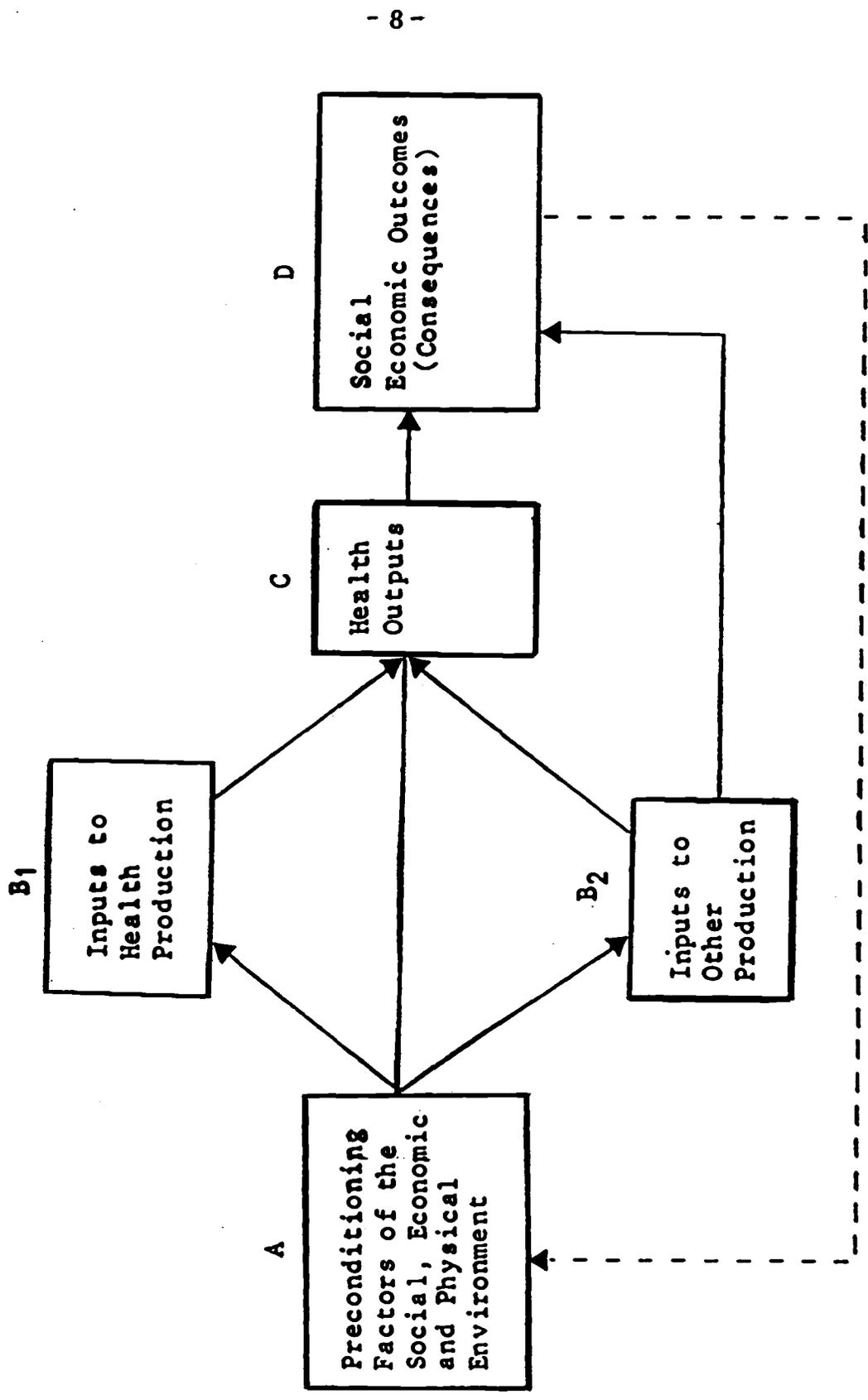
Since understanding and improving the human condition is what all of this is about, it is imperative that each of us continually examine how we are contributing, what our limits are, and where other expertise -- whether local knowledge, other disciplines, or policy-oriented -- is necessary. It is not a straightforward process; the interview which is quoted above illustrates how messy this attempt to understand complex human phenomena can be. Nevertheless, it is not permissible to hide in a statistics book with the excuse that this is too uncontrolled, or that qualitative data are a nightmare to analyze. Indeed they can be, but just as most biostatistics students soon get over their naive hope to immediately and intuitively understand varimax rotations of factor analysis, so we can take a deep breath and prepare to learn at least the right questions to ask in other fields of knowledge.

We've come a long way. Following are two diagrams from TDR-SER publications, ten years apart (WHO 1980; WHO 1991). The first shows a diagram from the "suggested" conceptual framework for research on the social and economic impact of tropical diseases. As you can see, it is quite narrowly economic, and while it is still reflective of one school of social sciences -- a particular type of economic analysis -- it is certainly not the only nor even perhaps the most appropriate conceptual framework for social science research about tropical diseases.

The second diagram comes from a meeting held earlier this year on the application of rapid assessment methods to tropical diseases. Although it continues to use some categories relevant especially to the "default" disciplines (medical science and epidemiology), the approach is much more global and allows for analysis of different levels of reality. The key column here is the last one: PURPOSE, which could have many more entries. If the purpose is to document incidence rates of cutaneous leishmaniasis among miners in the jungle, different approaches are necessary than if the purpose is to develop valid indicators of social conflict arising from differential access to treatment.

Finally, having begun an examination of the theoretical and ideological assumptions underlying the natural sciences and biomedicine in particular, and having accepted that no discipline has all the answers or even most of the questions, we may be ready for:

**Figure 1.** Conceptual framework for assessing the social and economic consequences of the tropical diseases.



(Source: WHO 1980)



**Step Three on the road to creating and sharing knowledge for action: resign yourself to long discussion and negotiations with co-researchers, funding agencies, and the policy makers you ultimately hope to influence, and, most importantly, with the people on whose behalf you are doing all this work.**

There are no easy answers. There are no fool-proof recipes. There are no magic bullets. One of the books I read to prepare for this talk is called "Biomedical Science and the Third World: Under the Volcano" (Bloom and Cerami 1989). I opened it, expecting a hard-hitting, polemical critique of the broken promises of biomedicine; I found that "Under the Volcano" implied *not* that time is running out, but that the answers to all kinds of problems are just bursting to come forward, to explode in a lava flow of science applied to ending human misery. The individual papers in fact addressed the issue from many perspectives, ranging from the immunology chapters with virtually no vowels to rather depressing economic analyses. Indeed, almost all of the papers were a good deal more cautious than the one generating the title, yet the overall optimism remains. It is one thing to understand that "multidisciplinarity" will likely entail not getting your own way much of the time, but the process of trying to see problems from different points of view and in a broader context than the germ theory of disease, for instance, allows is ongoing and difficult. The temptation to see the latest scientific advance as "The Answer" is extremely powerful.

Although the central purpose of this paper has been to challenge a simplistically linear view of the nature of scientific progress and to avoid replacing it with another simplistic view of "multidisciplinarity" as the new panacea, I would like to hold fiercely to the commitment and hope that underlie that title, beneath the complacency and the facile slogans. It is this commitment of medical scientists, social scientists, communities, and others that may provide the base from which to continue the discussions, negotiations, failures, and successes.

In his collection of essays *La otra voz: poesía y fin de siglo*, Octavio Paz (1990) discusses the threat that blind market forces pose to intimate human activity, such as poetry. He writes:

*Today the arts and literature are exposed to a distinct danger: they are not threatened by a doctrine or by an omniscient political party, but by an economic process that is faceless, soulless and without direction. The market is circular, impersonal, impartial and inflexible. Some will say that, in its own way, it is just. Perhaps. But it is blind and deaf, it does not love literature or risk, it does not know and cannot choose. Its censure is not ideological; it has no ideas. It knows of prices, not of values. (my translation)*

Science is also impartial and inflexible; science also has no ideas. But science as a human endeavour *is* ideas, and it is up to us to create and share those ideas, to imbue them with human values of justice and compassion. To do otherwise is to betray its promise, and ours.

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