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EXPLORING SUSTAINABLE RESPONSES TO THE HIV EPIDEMIC: GROUNDING RESPONSES IN PEOPLE'S USE OF LANGUAGE – A CROSS-CULTURAL STUDY OF RESPONSES

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Background

This essay on how people speak about their experiences with the HIV-epidemic and the way metaphors are used in responses to HIV/AIDS is based on a study done for the United Nations Development Programme (UNDP), HIV & Development. The study was done by a multidisciplinary team with the task of exploring the development of sustainable responses to the HIV epidemic. The work was a so-called "forward-looking evaluation". The team had a core group of researchers from Australia, Canada, Mexico and Norway, supplemented with local colleagues in the countries where the study was done. Three countries had been selected for our work: Zambia, the Philippines and Mexico. These countries reflect a diversity of regions (Africa, Latin-America and Asia). They are countries with different experience of the HIV-epidemic and its impact.

The study had a qualitative approach. The process of interpretive interactionism was applied (Denzin 1989). The primary means of data-collection for the evaluation was through interactive discussions held with selected participants from each country visited. This dialogue differed from the usual interview format, in that those interviewed were able to talk freely about what mattered to them, but the interviewers from the evaluation team were also free to pursue issues the team considered important; hence the term "interactive discussion", rather than "interview".

The interactive discussions aimed to explore the evaluation of the participants' own experiences of HIV and development, keeping in mind that the central question of concern was, "How can we move forward together?" The interactive discussions aimed to explore relevant issues through people's provision of "thick descriptions", as defined by Denzin (Denzin 1989: 83):

A thick description does more than record what a person is doing. It goes beyond mere fact and surface appearances. It presents detail, context, emotion, and the webs of social relationships that join persons to one another. Thick descriptions evokes emotionality and self-feelings. It inserts history into experience. It establishes the significance of an experience, or the sequence of events, for the person or persons in question. In thick description, the voices, feelings, actions and meanings of interacting individuals are heard.

Using interactive processes, the evaluators brought interpretations and understanding back to the participants in the process, both individually and in groups, and continued that exploration together.

Patterns of understanding were uncovered in this interactive process of interpretation. Such patterns were usually not conscious, but once they were identified they sometimes provided participants with powerful "Aha!" experiences: experiences which gave people insight into either useful types of language that they could further use to enhance their understanding, or which surprised people. Such experiences often involved discovering limitations and possibilities for moving forward.

The sampling procedures in qualitative research are different from procedures in quantitative research. In this case we used purposeful sampling, as defined by Patton (1990: 169). The selection of people to be included as evaluation participants for this study was therefore based on determining which people were most likely to provide high quality unpublished information which would
contribute to a better understanding of how approaches used in HIV/AIDS work function in practice. In each country, participants included people from the governmental sector, non-governmental organisations (including donor agencies), community groups, and grassroots movements. Needless to say, all evaluation participants were already highly involved in HIV/AIDS work.

The whole range of findings, conclusions and recommendations made based on the investigations and evaluation will not be described in this presentation. Interested readers are referred to the published book based on the comprehensive cross-cultural study (Parnell et al., 1996). This presentation will focus on what was discovered in the process of studying the language people used in conveying their experiences and sharing their reflections with the researchers. The reason why this presentation concentrates on the metaphors used in responses to HIV/AIDS is that the analyses of language, the participants' use of metaphors, gave the researchers as well as the study participants several "aha"-experiences and insight in HIV/AIDS responses. This insight has further triggered the researchers to link this HIV/AIDS-related study to recent theories of and research on metaphors. Theoretically, this area of research and theory development has been the subject of increasing interest in the 80s and 90s in a number of academic disciplines, including cognitive and clinical psychology, education, linguistics, artificial intelligence, anthropology, philosophy of language and philosophy of science (Ortony, 1993). This presentation can not do justice to the wide range of recent empirical and theoretical contributions in the field of metaphors, but by giving some illustrations from the HIV/AIDS evaluation study and the discussion of these data, the author hope to increase the readers’ appetite for what metaphors reveal about the mind and our lives.

**A Condensed Picture and Contextualisation of Metaphors**

The essence of metaphor is the use of one thing to represent another. As Turbayne (1970), drawing on Aristotle, puts it:

> Metaphor consists in giving the thing a name that belongs to something else; the transference being either from genus to species or from species to species, or on grounds of analogy (Turbayne 1970: 11).

Most people probably think of metaphors in connection with poetic imagination or rhetorical speech. This is because metaphors used in such contexts are often used in unexpected ways, in ways that surprise us. In poetry the metaphors are highlighted. But metaphors are an integral part of everyday language in any culture, and they are often so integrated in our ways of thinking and expressing ourselves, that the connections are often hidden to the conscious part of ourselves. This is equally true for metaphors used in scientific language (a point addressed later in this paper).

George Lakoff is a well known contemporary scholar who has written numerous papers and books in the field of metaphors. He challenges the dominant view on metaphors, including Aristotle's definition. While metaphor is typically viewed as characteristic of language alone, a matter of words, Lakoff and his colleagues point out:

> We have found, on the contrary, that metaphor is pervasive in everyday life, not just in language, but in thought and action. Our ordinary conceptual system, in terms of which we both think and act, is fundamentally metaphorical in nature. The concepts that govern our thought are not just matters of the intellect. They also govern our everyday functioning, down to the most mundane details. Our concepts structure what we perceive, how we get around in the world, and how we relate to people. Our conceptual system thus plays a central role in defining our everyday realities (Lakoff and Johnson 1980: 3).

From the time of Aristotle to the later works of Wittgenstein, categories were thought to be well understood and unproblematic. They were assumed to be abstract containers, with things either inside or outside the category. Things were assumed to be in the same category if, and only if, they had certain properties in common. And the properties they had in common were taken as defining the
This classical theory was not the result of empirical study. It was a philosophical position arrived at on the basis of a priori speculation. Over the centuries it simply became part of the background assumptions taken for granted in most scholarly disciplines. In fact, until recently, the classical theory of categories was not even thought of as a theory. It was taught in most disciplines not as an empirical hypothesis but as an unquestionable, definitional truth.

In a remarkable short time all that has changed. Categorization has moved from the background to the centre stage because of empirical studies in a wide range of disciplines.

Scholars such as Eleanor Rosli, Andrew Ortony, Mark Johnson, and George Lakoff, on theoretical and empirical grounds, reject that the mind is separate from, and independent of the body; reject that emotion has no conceptual content; reject that mathematics is a form of transcendental reason, just to mention some of the implications.

Dominant Metaphors and Some of Their Limitations.

Some concepts will be familiar to most health and social science oriented academics as they represent some everyday concepts in social research as well as in many health promotion programmes. They also represent concepts we found used by some of our interviewees or evaluation participants in Zambia, Philippines and Mexico. Consider the following concepts:

- input
- output
- analysing the situation
- testing
- fine tuning of programmes
- programming
- measuring effectiveness
- targeting
- intervention
- control
- expert

These concepts, and other like them, belong to the domain of engineering. When used within social sciences, we talk about "social engineering". Let us consider the single metaphor, the term, "expert". The idea is that an "expert", just like an engineer working with a mechanical system, can learn all there is to know about a particular situation, through observation, and then tamper with that situation, through "intervention", to make the whole thing "work better". No-one says that social systems are mechanical, but an implication of use of this metaphor is that the methods used to fix machines can, by and large, be transferred to the field of human development. Such simple use of metaphors may appear harmless enough. However, when they are put together within an overall metaphorical framework, they may come to dominate the ways people think about particular situations.

There would be no problem with use of these terms within the domain of "social engineering" if they enabled better understanding of different situations, and if they led to more effective responses to the HIV-epidemic. The problem is that use of this particular metaphorical domain has become so dominant among health authorities in most countries, in the World Health Organisation (WHO), in the U.N., and among donor agencies in general, that it leads to exclusion of other ways of talking about the HIV epidemic. There are many reasons why the "social engineering" metaphor is a dominant metaphor. One of the reasons is the position of the western positivistic tradition in science.
and world economy (a point that will not be elaborated in this paper). However, some of the reflections made by selected interviewees or evaluation participants will be presented here. As one participant from Zambia noted:

They used these methods to deal with smallpox. Now they're trying to do the same with HIV. HIV is far more complex than smallpox, but the language they use does not acknowledge that.

The result is that the use of this metaphorical domain has limited, not enhanced, understanding and the development of effective responses to the epidemic. Smallpox and a vaccination programme to eradicate the disease is different from sexual relations, from sexual attractions, from making love, or from sexual activity as a commodity for financial and material security. It is different from abstaining from sexual activity, and different from experiencing the loss of a spouse, a mother or father, sister or brother, daughter or son - or from seeing your neighbourhood change. It is different from grief, shame, hope, and belief in the future. These concepts can not be understood in terms of engineering or machinery metaphors. The way in which use of the "social engineering" metaphor has worked against the inclusion of many people's concerns within the epidemic, is intricately linked with culture and values. This was highlighted by Eduardo San Miguel, a human rights lawyer who was interviewed in Mexico:

Social engineering does not refer to social relations. It seems to be very technological, market oriented, reflective of state intervention versus participation in activity, with a high role for hierarchy. Authority without taking anybody into account.

Language consistent with the "social engineering" metaphor was typically and most often used by participants who were employed in National AIDS Control Programmes of the respective countries visited for the study and by people working for donor agencies - that is by those in control of funding a diversity of activities linked to prevention of HIV or help to those infected or affected by AIDS. Concepts linked to the "social engineering" metaphor were often used by authorities and funding agencies in defining terms and conditions for funding. The interviewees also described how this led to forms of project proposal writing and reporting which conflicted with participants' own experiences in working with people in their own contexts. Equally typical among the interviewees using concepts from this domain of metaphors, was the pessimism that most of these interviewees expressed as opposed to people from community organisations and grassroots initiated programmes.

When this information based on the individual interviews was shared with UN, WHO and donor agencies in each country visited, there was also a recognition that this type of terms dominated their agencies' ways of describing the epidemic and responses to it. In Zambia and Mexico, discussion amongst these agencies led to a recognition of the clash between this type of metaphors and their work with people in-country. Some participants noted, for example, that they have to work with people in one way and report back to their own international agencies in another way. The main frustration reported was with the agencies, and not with the people.

The notable exception from this pattern of responses was in the Philippines. Many participants there noted that they could happily use terms from within this metaphorical framework alongside the use of more inclusive, process-oriented terms which described their actual practice. To the extent that these terms clashed with their practice, which was often the case, this was not considered a problem. (Do they have a different history of dealing with "competing world views"? Or is this a reflection of the fact that the epidemic at this stage in the Philippines is still in its initial phase?!) Even if the "social engineering" metaphor was found to be dominant among "those in power" across countries, there was certainly a range of metaphors used. Use of metaphorical domains, rather than just single metaphors, was found to be a feature of many discussions about HIV. Apart from "social engineering", the metaphors centred around the following domains: "war", "building", "family" and "farming". Importantly, use of different types of metaphors seemed to vary between countries. This
may reflect different cultures and cultural experiences, but also may arise from different experiences of the epidemic.

Some words used by evaluation participants can be used within several metaphorical domains. This illustrates the importance of interactive exploration to identify patterns of meaning in the use of words. Words that are used in the domains of both "social engineering" and "war" include, "targets", "operations", and "interventions."

### The "War" Metaphor Domain

Recurring words used in the war metaphor domain were: fight, barriers, conflict, battle, shield, targets, power, power-imbalance, hostility, oppression, submission, victim, win. Within the war metaphor the perception of the enemy varies. The enemy may be the virus. Often, however, the enemy is perceived to be the HIV-infected person, either as the one who destroys others or as one who is already infected, degraded, made unworthy, demonised through being victimised and thus no longer one of us. A thick description of being degraded through victimisation was shared with us by a Zambian HIV-positive woman who was active within the church and who worked on a voluntary basis in hospitals, helping people with AIDS. Here are a few excerpts of her interview:

... the first time I opened up to those pastors' wives, I saw a judgemental spirit ... There are words still being used that should be removed. "Victim!" ... so people put a label on you.

The enemy may also be perceived as any people obviously associated with HIV-positive people, such as people in the gay community in Mexico. The popular view in Mexico is that AIDS is a disease of homosexuality in spite of the epidemiological fact that HIV has been rapidly increasing among women. The following quote is from a heterosexual lawyer who became suspicious in the eyes of his colleagues because he took cases for HIV-positive persons:

Don't come near me because I am going to get it from you (the homosexuality). The attitude of many of my colleagues is that homosexuality is "vampirism"... Social images of sexuality as the unnamable and filthy are reinforced by prejudice and intolerance ...

(Eduardo San Miguel, the National Commission on Human Rights, Mexico)

Amongst people engaged in effective and voluntary responses to the epidemic, the perception of the enemy is often very different. Here is an example from Zambia:

... the conflict is really a struggle for dominance and a struggle for resisting dominance ... of course we meet resistance, but we soldier on ... AIDS is a crosscutting issue. This is really about fighting the patriarchal structure. And if this is not recognised in the response to the AIDS-epidemic we will have no movement forward!

(Sara Longwe and Roy Clarke, private development consultants, Zambia).

Several of the so-called "change agents" or HIV/AIDS activists in the slums of Mexico City used a language full of concepts associated with war. But they were not aware of it. When the researchers shared their observations and reflections in interactive group discussions with those that we had already interviewed, many participants expressed "discoveries". Inma Rosado, (from the organisation Aspane) participating in one of the workshops we had in Mexico, expressed it like this:

There is a danger with the use of metaphors. Sometimes we use them firmly without reflecting on them. I realise I am always fighting. I am constantly talking about breaking the walls of the ghetto, to tear down barriers. I am thinking and functioning within the war metaphor and this is the first time I have stopped to reflect on it. The NGOs in Mexico are also fighting between themselves. This has been really valuable for me. I discover that I don't always need to fight, that actually a lot of the NGOs and others involved in responding to the epidemic can communicate and co-operate and have a lot in common in
spite of the diversity.

At this stage of the presentation it is pertinent to comment that of course "war" metaphors as well as "social engineering" metaphors may be both relevant and useful in some cases and under some circumstances. The problem we are faced with is when a single metaphorical domain dominates our understanding, our thought and action to the exclusion of other ways of thinking and acting.

The "Building" Metaphor Domain

The metaphor of building was used in several ways amongst evaluation participants, but was particularly noticeable amongst them in Mexico. It was used to illustrate construction and creation processes, as processes involving collective action and solidarity. The building was often seen as a home - providing sanctuary and protection.

In Mexico, exploration of the building metaphor revealed that building was associated with long traditions of neighbours and friends helping each other in building homes. It evokes such associations as "solidarity", "reciprocity", "mutuality", and "belonging in a community".

When discussing people's decisions about when to be open about HIV-positive status, concepts like "coming out" and "out of the closet" were used in association with the concept of building. Interactive reflection in the workshop in Mexico revealed that coming out can make you vulnerable because it could put you in the open with no protection, with no shelter, with the risk of losing belonging. Use of the metaphor helps make clear some connections between the issue of "coming out" and "enabling and supportive environments".

The participants of the interactive groups found it interesting to notice the way the building metaphor was used in Mexico, especially the connection between the inanimate thing (the object), the process (the process of building), the action - or rather the social interaction (solidarity), the function (shelter) and the feelings (for example feelings of security, belonging). This way of clustering phenomena (or making gestalts) was also evident in other contexts in Mexico, for example when discussing concepts like "models", expressions like this one was heard: "The model is the tool, solidarity is the energy". In this conceptual clustering reason and emotion go together.

Obvious in this way of using the building metaphor was the involvement, the sense of we, of togetherness in the process of creation. This is very different from the concept of "the expert" in the social engineering metaphor. In the "social engineering" metaphor action is actually left to the expert who is programming, intervening, manipulating others (defined as "they"). The expert is distant, not involved, ruled by reason, not emotion: the ideal of western conceptualisation of professionalism.

The "Family" Metaphor Domain

Language centring around the concept associated with "the family" was often used by participants in the Philippines. Use of this metaphor was typified in discussion about the fact that many successful projects started with very humble beginnings, with no clear understanding of long term goals or even general directions. People simply, "... came together" to explore what they might do. People work together, support one another, and grow together, just as children grow within a family.

There was a strong sense of nurturing new developments in a caring way in the Philippines. For example, many NGOs which have worked successfully on issues around the epidemic in Manila are now engaged in encouraging the development of NGO initiatives in other regions of the country. The use of validation and encouragement was seen as important. One NGO worker drew attention to the importance of what she called "The principle of giving them small successes":

For example, with kids learning to walk. One or two steps when they don't fall. Something
of value where they can see. So they glean some satisfaction where they've started to move. Think may be three or six months later what they'll be doing.

The "Farming" Metaphor Domain

Farming metaphors were deeply ingrained in the thinking and acting of community programmes and "grass-roots" initiated responses to the epidemic in Zambia. Several of these responses were almost invisible to the donor-agencies in Zambia because representatives of these responses could not formulate their existence in "the proper language", that is in the format of the social engineering metaphor. They were unfamiliar with the language and auditing system of the donor-agencies, or they made plans, but "could not" stick to them. Thus they had very little financial support, if any, from "those in power". Paradoxically representatives of these responses to the epidemic were the ones we found to have achieved the most. They were the ones with the highest level of energy and involvement. Their responses were future-oriented and illustrated hope in what many other people would see as the most grim of circumstances, in an area of the world most severely affected by the epidemic.

It is like growing something: it doesn't take a day. You must be prepared to wait. You need to nurture and care for the tree to yield fruits which you may never yourself get to see.
(Sister Ponga, Zambia)

Farming in African societies is often done by women, and is connected to sustaining life through providing food for family members. It involves responsibility, care, patience, knowledge, attentiveness, and being sensitive to the surrounding environment (changing weather conditions, droughts, floods, access to water, etc.). Farming in the African context is not mechanical. It means interacting with natural surroundings and understanding interdependence. It also means that even if you have to put in a lot of work, the product of your work will not appear immediately, but the product of your work may still be essential for community survival.

Farming is not linear: it is not a question of putting in the seed and waiting for the result. Conditions change and responses must change accordingly. Farming follows certain cycles and is process-oriented.

Kwasha Mukwenu, Matero in Lusaka, Zambia

A presentation of this format does not give much room for many "thick descriptions", but a part of one interactive interview session will wind up this paper. Some background information is needed. In sections of the city of Lusaka, the authorities estimate that 40% of the population are HIV-positive. Matero is a neighbourhood in Lusaka severely affected by the HIV epidemic. In this neighbourhood people are dying every day from AIDS. Taking care of all the orphans was and is a growing problem. Extended family members no longer seem to be able to take over responsibility for orphaned children, either because they are too far away or because they themselves have their own problems. Many children in Matero live in child-headed households.

In 1991 several women in Matero were concerned about the large and growing number of orphans in their community. The orphans were children they knew and who were playing and/or attending school with their own children. Three women agreed to raise their concern and discuss it with others. Together they started Kwasha Mukwenu as a community organisation. (Kwasha mukwenu means: Help your friend who is in need.)

The core group of women in Kwasha Mukwenu at the time of the study were 30 widows who had lost their husbands due to AIDS. Many of these women knew that they themselves were HIV
infected, or they assumed that they were infected. These women cared for 1049 orphans in their own neighbourhood. The women had divided the neighbourhood into quarters or sectors, following the principle that children should stay where they feel at home, where they know each other and the "mother" who cares for them. The children should know they belong in their neighbourhood.

When we came to Matero and Kwasha Mukwenu's premises (rooms belonging to the local church) in October a few years ago, it was lunch time. Approx. 30 children of varying ages were seated on the floor of a little room, having their lunch. (The food had been cooked in the local homes of the women and brought to where the children were fed.) The women who were feeding the children were interacting with them the way caring mothers would with their own children; with smiles, guidance and caring attention. You instantly felt the warm atmosphere of the place. Seven women received us. Rose Mwitelela was their spokeswoman, since most of the women were hesitant about speaking English at first.

How did these 30 women get the energy and commitment to do their work of caring for more than 1000 children? Here are the words of Rose Mwitelela:

We are planting the seeds of love in these children so that they will grow up and be caring persons. We know that not all seeds will grow, but we have to put our faith in the future of these children. They will also be the ones to take care of our children when we die and to nourish the seeds of love in them."

As we left, we saw children leaving for home; many were holding hands, laughing and smiling.

References