SUPPORTING WOMEN WITH HIV INFECTION AND THEIR NEWBORNS IN COMMUNITIES IN AFRICA AND ASIA

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Introduction

Gender inequality and poverty place women in Africa and Asia at high risk of becoming infected with the HIV virus. Women take immense risks simply to feed their children. The social position of many women also depends on producing healthy children. It follows, then, that avoiding disclosure of an HIV infection by postpartum mothers may be a necessary strategy to prevent anticipated economic and social hardship.

It is now recognized that, if an HIV-infected mother breastfeeds, her infant is at risk for infection. However, the degree of risk associated with different infant feeding methods is unclear. So, the decision as to whether or not to breastfeed is neither medically nor socially simple. The status of the available scientific evidence, the desire to promote a fully informed choice among infant feeding methods, pervasive poverty, and the norms, values, and social context of the culture in which a mother feeds her infant makes the feasibility of implementing a health-related project at a local level complex. Not simply associated with an infant health outcome, HIV-related decisions may be inextricably connected to the very survival of a woman and her children. It follows, then, that interventions must be tailored to particular local contexts, be multifaceted and designed to support an HIV infected woman and her infant by strengthening her family, her household and community.

Goal of the Paper

This paper has focused on what has been learned from implementing programs at a community level, what scientific and cultural data are available to guide interventions, and, if undertaken, what steps must guide community involvement programs. Ultimately, the goal of this paper is to address the feasibility of implementing a medically based, community-wide Mother-to-Child Transmission (MTCT) project. To accomplish this, the paper has several complementary purposes:

- to gain insights from a literature review of both successful and unsuccessful projects that engaged local groups and communities in support of a health-related problem;
- to describe relevant examples of prototypical infant feeding patterns in different societies within the context of mothers HIV infection;
- to critically examine the issues involved in establishing policies and programs regarding infant feeding practices of HIV infected mothers, particularly raising questions about cross-cultural viability;
- to review the issues involved in counseling HIV-infected women with infants;
- to analyze the forces that health planners must consider in assessing and strengthening individual HIV program elements and developing community wide interventions, and, finally,
- to cull from the analysis lessons learned towards making recommendations for working with communities in support of HIV infected women and their infants.

The Model

In July, 1998, at the 12th International AIDS Conference, the Positive Action Programme, a new public health initiative was announced. The project was designed to help HIV-positive mothers in Africa, Asia, and Latin America (where there is high HIV prevalence) increase their chances of having a healthy child. Co-sponsors USAID and UNICEF assumed a major role at the country level, assisting governments and other partners to carry out the initiative. WHO, another cosponsor agreed to provide technical support and develop standards of care. The intervention involved providing an opportunity for mothers to be tested for HIV infection, and for those who test positive for the virus to take the short-term regime of AZT, known to significantly reduce mother-to-child transmission (MTCT). **Postpartum HIV+ women would be counseled about infant feeding; and offered infant formula, free of charge.** A global pharmaceutical company agreed to provide packaging and distribution assistance as well as assisting in the design and implementation of the individual counseling for women and their families and educational and programmatic support.

Staff of a well-know international non-profit organization met in early 1999 to discuss the importance of involving the community by providing them with information, counseling and support of the MTCT initiative. To respond to the need for broader consultation and concerns about MTCT, it was suggested that a nine-month study be conducted in collaboration with African organizations in Botswana and Zambia. It is being conducted in two stages: community-based research and a consultative in two countries in sub-Saharan Africa. The overall objective is to enhance the effectiveness of initiatives to prevent MTCT of HIV through a program that provide a better understanding of the information, education, counseling, and by providing support to communities.

The international agency agreed to conduct a literature review of projects and methods that were successful in mobilizing communities and groups in support of women with HIV and their newborns. The paper was to be part of background information disseminated at the 2000 International AIDS Conference in Johannesburg, South Africa. Its goal was to enhance understandings of staff of NGOs who were participating in the MTCT pilot projects about benefits and challenges of community mobilization to support such a medical program.

Review of the Literature

More than 20 years of accumulated findings from projects and studies in rural development, gender, health and social anthropology have profound implications for the proposed intervention for HIV-infected women and their infants. In this review, these findings are utilized to critically think through the complex issues surrounding HIV for women and their infants in diverse cultural and social contexts. Examples are offered of approaches and projects gone awry, and those that are successful. They represent what can be done to implement community projects and suggest effective methods to do it.

The literature reviewed for this paper is from rural development; participatory action research gender; disease and illness; family planning; infant feeding; maternal, child and reproductive health. Although some examples (from agro-forestry, safe water projects) may appear to be far

afield from HIV interventions, the central issues and themes in all of the examples parallel those of the proposed HIV model.

The Model-T "Transfer of Technology" Approach

From the 1960's through the 1980's scientists have used a Model-T Transfer of Technology (TOT) approach to rural development (Chambers, 1997). TOT takes a standardized project designed for one socio-cultural, environmental and technological setting and applies it to another one that is often very different. The standardized approach has both benefits and disadvantages. When conditions are appropriate, a standardized TOT approach can be successful. The use of blackboards in schools in India and the transfer of the Mark 2-hand pump for water are examples of successful projects. The benefits of standardized projects derive from the fact that the physical technology is widely applicable. Another criterion necessary for success include a tightly regulated and predictable target community where critical environmental factors can be controlled. In addition, the goals and objectives of the project must not conflict with the norms and values of the community.

In some settings in Asia and Latin America, the green revolution successfully utilized a TOT approach to increase agricultural production by transferring high-tech methods directly to farms. Utilizing new varieties of wheat and rice, and with access to markets for crops, some farmers were able to successfully use irrigation, fertilizers, and pesticides and mechanized farm equipment-- all Western technological innovations (Chambers, 1997). In situations where standardized approaches are successful, the recipients must also perceive the need for the TOT, have the support of the community, or at least not be thwarted by them, and have the capacity to use the recommended practices or technology. Large numbers of subsistence farmers in Asia and Latin America who raised food for their families on marginal, rain-fed land, did not benefit from transfer of agricultural technology of the green revolution (Wolf, 1986). Thus, when conditions are appropriate, standardized TOT approaches have been successful. Where local conditions are vastly different, TOT or standardized projects, intended to improve the lives of community members, not only failed, but some have had a major negative impact.

Unanticipated Consequences of TOT

Standardization, according to Chambers, helps spend money fast. Unanticipated consequences of funding pressures are illustrated in a national reforestation project in the Philippines. With loans from world banks, the Philippines Department of Environment and Natural Resources was under pressure to spend these funds and rapidly scale up the project. With no time to develop a variety of species, the agency decided to only plant what they had on hand, *gmelina arborea* seedlings. Unfortunately, planting this single species inhibited undergrowth, resulting in the erosion of the soil. It has been estimated that the disruption of the grasslands involved in plating these trees produced greater soil loss than the surviving trees prevented. Widespread use of *gmelina aborea* also increased the threat of agricultural pest infestation. This suggests that one needs to be as aware as possible of the negative side effects of any intervention before attempting it (Chambers, 1997).

Other unanticipated problems have occurred as a result of utilizing a standardized TOT,

approach. For example, in Ghana, a rice irrigation project and the construction of multi-purpose clay core village dams eliminated guinea worm disease through improvements in the quality of available water. However, the abundance of water from the irrigation project had a secondary effect of causing an epidemic of mosquito-borne *filariasis* (elephantitias). As a result of the dams, *schistosomiasis haematobium* became a widespread health problem (Hunter, 1997).

Divergent Perceptions

Rural development experts often have a set of assumptions about the community that creates barriers to a project" success. As a result of an evaluation of a four-year national reforestation project in Pakistan, it was discovered that the foresters' preconceived ideas of who could best implement the project negatively affected its success. Foresters believed that only owners of large farms would be interested and able to participate in the project. They did not know that individuals with smaller farms already had multi-purpose native plants, wanted to plant more of them, and knew that more fuel wood would reduce dung burning. Such factors made small farmers more amenable to implementing the project.

The Pakistan project is another example of how narrowly focused experts' explanations and assumptions obscure the complexities of decision-making among local people. Initially, conclusive evidence did not exist about the link between small farmers and the macro reforestation project. No one did the research. Lacking this information, government foresters remained unaware of the small farmers' interest in participating in the project. They mistakenly continued to target large farmers for the interventions, jeopardizing the success of the program (Chambers, 1997). Both the Pakistan reforestation and the Ghanaian ground water projects used incomplete and contradictory data and ignored the complexities of the interventions. As a result, the impact of such factors as the local conditions, social relations, and indigenous knowledge was trivialized.

Interventions to treat leprosy among the Hausa of Northern Nigeria present another striking example of divergent attitudes and behaviors of Western change agents and indigenous people. In the l960's, a comparatively high prevalence of leprosy existed among this population. Hausa had little fear, stigma or disgust towards individuals with the disease. People lived with their families in compounds and had a normal life until the disease was quite advanced, when they became beggars and, in the Islamic tradition, obtained alms from the community. Following Western norms and practices, Christian missionaries feared and loathed lepers, and treated them by isolating them in hospitals. For the Hausa, this was tragic. These attitudes and the culturally inappropriate public health interventions increased Hausa suspicions, myths and fears about the missionaries motives (Shiloh, 1965).

The use of a traditional surgical treatment for correcting congenital hip disease among the Navajo is a classic example of a standard medical approach that resulted in harm. To treat the condition in adults, traditionally, surgeons fused the hip joint in order to prevent the development of a painful mono-articular arthritis. This procedure returned the Navajo patient to the community as severely disabled. The patient was unable to sit on the floor and eat with the family; they were unable to ride on a horse or herd sheep, which required walking long distances over very uneven ground. An anthropological study documenting the social and physical disabilities resulting from the surgery, encouraged physicians to develop a new procedure. An acetabulum was constructed

from part of the hipbone. This procedure enabled a patient to return to the family and community as a fully functioning Navajo (Rabin and Barnett, 1965).

The Pakistan and Hausa experiences exemplify how the TOT model too often represents the outside professionals' perception of social reality in opposition to those of community members with whom they are working. Ignoring the social context can undermine the objectives of a needed intervention and result in negative side effects. In the case of the Navajos, the convergence of a medical and a social approach to disease, ultimately, resulted in enormous benefits to patients, their families and the community.

Participatory Approaches

In the l970's and 80's assessments of the outcomes of hundreds of rural development TOT projects identified serious limitations of this approach (Chambers, 1983; Cernea, 1985). Insights that emerged from reflecting on the successes and failures of agro-forestry, as well as from the analysis of applied social anthropology resulted in participatory approaches to learning and action. Participatory action research emerged as a more appropriate and effective method for solving local problems.

Participatory action research adapted the philosophy and methods of the Brazilian educator Paulo Freire (1968). Professionals or change agents enter into a collaborative process with community people to: l) reflect on their life situation; 2) examine the root causes of these conditions as well as the consequences; and 3) develop a plan of action to address the problem s that have been collectively identified. Such an approach strengthens the community or group's critical awareness of the causes of their problems, encourages a belief in the possibility of change, and a willingness to work to solve problems through the development of direct action (Minkler and Cox, 1980). While this may appear to be similar to traditional organizing approaches for social change, Freire's method tries to minimize the paternalistic aspect of other organizing approaches. The social change agent in this model acts as facilitator (Ibid.).

Despite the good intentions of professionals who use it, the TOT framework inhibits the identification of constraints that individuals experience in efforts to improve their lives. Conversely, the TOT approach does not utilize methods that would strengthen people's capability to improve their lives by removing forces that thwart them (Eade, 1997). In contrast, participatory action research enables local people to share their perceptions, knowledge, and insights about a problem. Collaborating with professionals, they can plan, act, monitor and evaluate interventions that affect their lives. The insights gleaned from the literature review show that, often what is identified as the initial problem and its potential solution, will radically change when the perspectives and options of community members are integrated into a project's design. When individuals participate in the process, it is much more likely that the outcomes will be supported and sustained. This approach has been successfully used in recent efforts to increase agricultural productivity among subsistence farmers. New technical opportunities are combined with traditional agricultural practices to produce sustainable farming (Cernea, 1985).

Implications of Participatory Action Research for Women

In some societies, culturally specific norms inhibit the discussion of some problems, making Peoples' participation initially difficult. Low status and multiple constraints on women's ability to act independently may make them reluctant to discuss some of their problems because, among other issues, they are concerned about confidentiality and retaliation. For example, in India, the Self-Employed Women's Association (SEWA) initially focused on representing unorganized women tailors. As a result of SEWA's in-depth discussions with these women, critical, basic unmet needs were identified that differed from the initial objective of the project. For example, SEWA learned about the inadequate sanitation facilities in the women's home village that forced community residents to use open spaces. Out of modesty, women would only use the fields late at night and before dawn. Waiting for long periods resulted in bladder and bowel infections. Limited availability of water, particularly during menstruation, caused additional discomfort, as well as hygienic problems. Rape was reported as a common occurrence when women were alone in the fields at night and pre-dawn. Shame, embarrassment, and the lack of assurance that this information would be treated with confidentiality prevented them from initially discussing these problems. Sharing similar backgrounds with the women, SEWA's staff developed a relationship of trust with them. Overtime, SEWA learned about the women's physical suffering and sexual violence that was exacerbated by village sanitation (Kabeer, 1994). A conventional, expert-led, single-target approach would never have uncovered this critical issue to women.

Social Influence: Who is the community?

To support a change process, it is important to identify the sources of social influence in a community in order to educate, train and encourage mobilization for social action. In Jodhpur, India the Women's Development Program (WDP) worked to build a coalition of women to pressure local institutions about issues of importance to them. Initially, front line staff with a similar background engaged local women in a discussion about how their low social and economic status affected them. WDP provided women with information, education and training about what they could do to improve their condition. Organized into a pressure group, the women were introduced to local officials who had the power to meet their demands. A major social problem identified was alcoholism among men that led to widespread wife beating. The women mobilized for a community meeting where they succeeded in instituting policies to stop the public consumption of alcohol. Nevertheless, by refusing to intervene in domestic disputes, the police continued to uphold the sanctity and the dominance of the domestic sphere for men. At a second meeting, where influential village elder men were invited and supported the women, the police agreed to prosecute drunken husbands who beat their wives (Jain in Kabeer, 1994, 244).

Another successful example was the collaboration of an NGO with influential community members from village India that resulted in a decrease in the occurrence of female infanticide. The NGO's research elicited an oral history of female infanticide. Dais (traditional birth attendants) were often paid to kill newborn females. Parents were unwilling to discuss the practice with NGO staff. Some dais, however, reported that they illegally engaged in female infanticide as a result of their impoverished condition. Dais were poor because they received meager payments for attending births, especially for the birth of a female. Fathers often pressured them to kill newborn

female infants and threatened them with economic and social sanctions as well as physical violence.

On the basis of a series of discussions with NGO staff, the dais suggested conducting a demographic survey in the village and establishing a watchdog committee consisting of diverse community members who were opposed to the practice. The committee agreed to monitor the data gathered, raise awareness about female infanticide, and apply pressure to change the practice. The dais decided to create an orphanage for unwanted female infants. Additionally, the NGO, moreover, established an economic program for dais in that community (Murthy, 1998). This further reduced the financial incentive to continue this practice. The participatory action research method, as seen in this case, used dialogue and critical reflection between NGO staff and local people in an effort to uncover the cause of a problem and mobilize them to change it. Multiple, sustained supports from the NGO ensured the project's success.

Trained village health workers have been shown to be successful in promoting breast-feeding, immunization, oral re-hydration, and infant growth in South Africa and elsewhere (Kuhn & Zwarensten, 1990). In Honduras, *promotora* (i.e., campesino women trained as health promoters) worked through Housewife Clubs in villages to improve sanitation. In every village where there was a *promotora,* members of the Housewives Clubs began to boil their water, thus eliminating the major source of gastro-intestinal illnesses (Minkler & Cox, 1980).

In a community study of trained traditional birth attendants (TBAs) close to the capital city of Accra, Ghana, it was found that women trusted TBAs more than physicians, nurses, etc. TBAs successfully provided patient education and encouraged women to go to the health centers for preventive services as well as for high-risk pregnancies. However, the problems were that their recommendations often were ignored because of financial limitations, that they lacked transportation, they feared disrespectful and received painful treatment by medical personnel. Because of these obstacles, TBAs routinely continue to perform the high-risk delivery, although they had been taught to refer patients to professionals who could provide higher levels of care. Similar findings of factors influencing women's decisions to seek higher level health care that are outside of the midwives' control are reported throughout the literature. It was suggested that trained traditional birth attendants, under such circumstances, may make a contribution to lowering maternal mortality rates by health promotion, rather than disease intervention (Eader, 1993). Clearly, to effectively utilize their abilities and skills, midwives have to be supported by local and national officials.

Fear of Disclosure/Confidentiality and traditional providers

Fear of disclosure and lack of confidentiality on the part of traditional health practitioners or public health workers may strongly influence a pregnant woman's decision not to take an HIV test and the decision as to how she will care and feed her newborn. Similarly, a study in Pakistan found that patients were generally unwilling to disclose that they were undergoing or had received TB treatment because of a perception that tuberculosis was incurable. None of the young women disclosed their infection for fear of being ostracized or that they would be perceived as unfit to marry. Despite the complex situation of these young women, health workers provided little counseling and education about TB and its treatment. Some advice was given based on the Asian

humoreatic system (e.g., on cool and hot foods). However, other advice was culturally inappropriate. Patients experienced increased feelings of isolation and abandonment and failed to return for treatment (Khan et al., 1999).

Attitudes of traditional health providers: Can training create change?

Indigenous health providers, as well as Western-trained health workers, share attitudes, values and norms of the communities in which they practice. In an intervention with traditional midwives to improve post-abortion care services in Morelos, Mexico, their beliefs, attitudes, concepts and experiences with abortion were initially elicited (Billings, 1999). It was learned that midwives, shared community norms of blame and held punitive attitudes towards women who both induced and spontaneously aborted. Utilizing this information, the training curriculum not only included basic skills to identify and stabilize women suffering from complications of abortion, but also addressed community beliefs about women who had abortions. Pre and post-tests and adult learning assessments revealed that midwives learned basic skills and showed caring for patients. Other barriers to incorporating midwives into the post-abortion care services were documented and addressed. For example, when midwives accompanied a woman to a hospital, they felt ignored and badly treated by the staff. Health care providers also needed to be educated about developing trust with midwives. Support from higher levels in the health care system reduces the risk that midwives will be the target of punitive and legal actions when they stabilize a woman with severe bleeding, accompany her to the health center or hospital, or otherwise assist her with lifesaving care.

Identifying the Change Agents: a Cautionary Note

The discussion so far has highlighted that, in successful projects, NGO-initiated discussions with community women or traditional midwives uncovered highly sensitive problems and solutions that resulted in positive social change. Rather than risk making incorrect assumptions, it is critical to carefully analyze the situation to ensure the selection of the appropriate group or groups with whom to form collaborative relationships. Prior to initiating an intervention, an understanding is required of the hierarchical relationships within the community, specifically the roles, status, and positions of individuals and groups. It is particularly important to understand the place of women in the hierarchy so as to avoid reinforcing structures that maintain power over them and or exclude them from participating in decision which affect them. Among the Tuareg, a semi-nomadic, socially stratified, Islamic people in the Republic of Niger, West Africa, herbal medicine women have a marginal social position. By assuming roles as mediators and facilitators and avoiding challenging male authority, these herbal medicine women are able to work closely with high status, Islamic scholars. However, being relegated to this role sometimes results in compromising the interests of women (Rasmussen, 1998)

Research on social networks suggests that groups who naturally collaborate can be used to identify specific issues and be mobilized to participate in a project or action. (Gujit & Shah, 1998). Large public meetings are useful for sharing information, but they are inappropriate when that information contains sensitive and potentially volatile issues such as sexual abuse and battering, female infanticide, reproductive rights, or HIV/AIDS. The female infanticide case illustrates that one to one interactions and social networks can be used more appropriately to intervene on sensitive issues.

The use of traditional healers in AIDS and STD health initiatives has been extensively debated in the literature (Green, 1994; Farmer, 1997). Unlike Western-trained health care providers, traditional healers are an integral part of the particular culture in which they practice. They take a holistic approach to illness and health as compared with the more narrowly focused bio-medical perspective. For these reasons, traditional healers are thought to be an appropriate bridge to Western-trained clinicians and health care facilities. As with other ritual specialists, the relative power, authority and the control that traditional healers exert over individuals and groups must be evaluated prior to mobilizing them for a health care intervention.

Stigma and blame are often a component of traditional healing practices. For these reasons, in Zaire and elsewhere, many people avoided consulting traditional healers (Schoepf, 1993; Symonds & Schoepf, In Press). Healers to identify the causes of disease and adversity use divination, spirit medium, among other methods. Usually, the cause is found to be in evil actions of persons or spirits, or some unconscious violation of a norm or rule. In many African countries people commonly believe that STDs and AIDS are caused by someone who "sends the sickness through sorcery." Attribution of blame is integral to the belief system of some African peoples. Community leaders and family elders, particularly men or mothers-in-law, can potentially identify the responsible person from the hints provided by a healer (Ibid.). For these reasons, safeguards must be established before initiating community mobilization to support HIV infected women or working in other ways with traditional healers. Collaboration with healers or other powerful groups should not be adopted, as Schoepf cautions, as a low cost panacea to the fact that stand-alone, TOT, health programs do not accomplish their goals" (Op. cit.).

Summary

In Table 1 below, the two approaches to social interventions -- the TOT and participatory models are set out. As described in the literature review, the TOT model is a standard pre-planned approach that is designed to be applicable to all targeted socio-cultural contexts. Where it is most successful, the technology and practices to be introduced must have broad applicability that is considered to be valuable by the community.

With the TOT approach, outside professionals introduce new technology or procedures to a community. Through consulting and training, members implement the approach. The planners and implementers, sometimes in collaboration with formal authorities, usually conduct some research on the applicability of the project outside the community. When the intervention faces problems or fails, the data used to design and implement the project has been shown to be flawed, distorted, or incomplete. Another problem with this approach occurs because the planners are unwilling or unable to change their preconceived perception of the community and its needs and desires. Poor planning occurred during the forestry project in Pakistan. Often elements of the new intervention are in conflict with the group or the entire community's norms and values. The missionaries' response to leprosy among the Hausa in Northern Nigeria, and their method of treating it, demonstrates profound cross-cultural perceptions of the disease, its cultural meaning, a community response.

Standardized interventions are often not targeted at the appropriate recipient, such as occurred during the Pakistani project. Furthermore, when applying

the TOT model, what the outsider's view as a real problem may be inconsistent with those views of community members. Finally, the secondary effects that result from the change may have a devastating impact on the community. Negative side effects resulted during the reforestation project in the Philippines and the rice irrigation project and multi-purpose clay core village dams construction in Ghana. A negative impact also occurred when surgeons fused the hipbones and severely disabled their Navajo patients, resulting in their inability to function in important aspects of community life. However, as a result of the findings of social researchers about the severity of the surgery's side effects, physicians were encouraged to develop a new procedure that improved the functioning of their patients.

A participatory approach is required when the intervention is complex and has wide-ranging implications for the targeted culture, including changes in the community's norms and values. A participatory approach does not focus on individuals or group analysis of problems. It begins with a process to uncover the broad social and cultural conditions of a situation that may be both cause or consequence of the problem (Yeich, 1996). The major part of the planning process involves a community assessment that is the beginning of the change process. Thus, the process engages members of the community in on-going dialogue that results in the development of a critical awareness of the problem and recommendations for actions/activities to solve it.

Community members are involved in all phases of the intervention beginning with data gathering and planning. They are perceived as partners of a process that helps build their capacity to develop and sustain the project. Often the initial outcomes may be modified and changed due to a better understanding of the real needs and desires of community members. This approach assumes that different groups in a community may have conflicting interests or power (such as healers, Islamic scholars, and mothers-in-law) that might resist changes that can threaten their interests. The process usually evolves as action research in that there is on going evaluation and modification as a result of feedback from the community.

Table 1

Two Frameworks of Social Interventions
(adapted from Chambers, 1997)

Characteristics	**TOT**	**Participatory**
Method	Blueprint	Process
Philosophical Approach	Planning	Participation
Goals	Pre-set, closed	Evolving, open
Decision-making	Centralized	Decentralized
Analytic assumptions	Single-issue/single-focus	System, holistic
Methods, rules	Standardized, universal	Diverse, local
Technology	Fixed package	Varied choices
Professionals' interaction with local people	Instructing, motivating	Enabling, empowering
Local people are seen as	Beneficiaries	Partners, actors
Outputs	Uniform Infrastructure	Diverse Infrastructure
Planning and Action	Experts/Professionals: Top-Down	Local Capacities Bottom-up

Lessons learned from the literature review

TOT may be used when:

- Widely applicable physical technology is applied and critical environmental factors are controlled
- Recipients perceive the need;
- There is community support, and
- Goals and objective are consistent with the community's norms and values

Avoid:

- Intervening without anticipating negative consequences (side effects) from intervention;
- Narrowly focused expert explanations and assumptions that obscure the complexity of decision-making by local people;
- Inappropriate attitudes and culturally incorrect interventions that can generate suspicion myths, and fears in local people.
- Poor perceptions of social reality that are in opposition to those of community members;
- Ignoring the social context that can undermine the objectives of a needed intervention and result in negative side effects.

Understand:

- Hierarchical relationships within the community, specifically the roles, status, and position of individuals and groups.
- Place of women in the hierarchy so as to avoid reinforcing structures that maintain power over them or exclude them from participating in decisions that affect them.

Consider:

- Social change agent as facilitators;
- Participatory action research to enable local people to share their perceptions, knowledge, and insights about a problem;
- Identifying the sources of social influence in order to educate, train, and encourage mobilization for social action;
- Creating opportunities for NGO staff, influential individuals, and local people to dialogue, critically reflect, and collaborate in an effort to uncover the cause of a problem and mobilize them to change it;
- Developing multiple and sustained support from NGOs;
- Analyzing the situation to ensure the selection of the appropriate group or groups with whom to form collaborative relationships; and
- Groups and social networks that naturally collaborate and can be used to identify specific issues and be mobilized to participate in projects or actions.

HIV infection in the Context of Infant Feeding

Cognitive and affective dimensions of behavior underpin the ideas, beliefs and assumptions held by women in all societies. Culturally constructed, infant feeding patterns reflect the norms and values of a particular community, including women's relative power and authority, and their ability to make independent decisions and act upon them. Findings from a four-country study of infant feeding patterns show the care with which women choose and prepare infant foods that are thought to ensure health and well-being (Winikoff et al, 1988). The following excerpt from the lyric poem Song of Lawino by the East African poet Okot p'Bitek illustrates traditional views on breastfeeding. It suggests a cultural proscription for breast feeding on demand in sickness and in health.

> When the baby cries, let him suck from the breast.
> There is no fixed time for breast-feeding.
> When the baby cries, it may be he is ill.
> The first medicine for a child is the breast.
> Give him milk. And he will stop crying (Latham, et al., 1988).

Cultural differences are also reflected in the ways in which women care for their sick infants. Mothers have models of illness and health that may include Western bio-medical theories of disease causation, humoral theories balancing hot and cold properties, and a number of folk and popular theories for self treatment (Van Esterik, 1989). Women respond to infant sickness according to their past experiences, including their infant feeding practices. In Thailand, for example, glucose mixtures, tonics and appetite stimulants and the use of laxatives and suppositories are common, particularly for infants being fed formula. Women use laxatives for formula fed infants because the hard, dry stools produced by a formula fed infant is seen as a sign of constipation compared with softer stools of a breast fed infant (Van Esterik, 1989).

Utilizing a participatory research approach, successful interventions build upon women's knowledge and experience and seek to reinforce their positive attitudes and patterns of infant feeding. To design culturally-specific and appropriate strategies for HIV infected mothers and their infants, it is, therefore, critical to understand how lactation is managed in different cultures. This includes attitudes towards, and use of, wet nursing and milk banks, as well as ways to care for sick infants.

In the study conducted in Colombia, Indonesia, Kenya, and Thailand, wet nursing was generally viewed as a form of emergency insurance or short term help for a mother having difficulties or to save an infant whose mother had died (Van Esterik, 1989). In the rural outskirts of Semarang, Indonesia, women cited Moslem restrictions on wet nursing. However, like the women in the rural community or Yoruba in Nigeria, they would breast feed another infant, if the natural mother had died. Women did express concern over contagious diseases and whether another woman's breast milk would agree with the child (Adetugbo, 1997).

Among the Yoruba, the sister of the child's father or a senior wife, usually an older woman, can be a wet nurse if the relationship is friendly and their "blood can mix well." (Adetugbo, 1997). Infants are thought to require water and herbal preparations, pre lacteal ritual feeding, and early supplementation. These practices contribute to a high prevalence of diarrhea and consistently high

infant mortality in this community. Expressing breast milk is culturally unacceptable, as it is thought that it could be used to poison, bewitch, or otherwise harm a mother and her infant. When asked, men report not knowing of the practice. Western-trained health workers believe that expressed milk becomes contaminated and sours after three hours. Formula introduced into this setting of mixed feeding is likely to have negative and widespread effects, if it influences the feeding patterns of the broader community of women. Consequently, it could produce an increase in infant mortality and morbidity community-wide.

In comparison, among the Javanese and Thai mothers of Chinese ancestry in that same study, breast milk can be shared between infants of the same, but not the opposite sex. Thai rural women allow their newborns to be breast fed by a woman, often related, who is locally recognized as a good nurturer. This is thought to establish a good habit for the breast-fed infant. In Nairobi, grandmothers breast fed their own and their daughters' infants. There, breast milk is considered a conduit for ancestral essence or power (Van Esterik, 1989). Decisions about wet nursing the infants of women with HIV must include the need for a woman of the same lineage or ethnic group.

In many cultures, the decision to stop breast feeding or use supplements is not necessarily those of the mother alone. Breast feeding in Zimbabwe is bound up with core cultural values (including sexual relations) that support universal breast feeding for a relatively long duration. Grandmothers and aunts must approve a mother's decision to stop breast feeding. If a husband is away, the woman may not stop breast feeding unless he has left instructions. Cessation of breast feeding implies that the woman is involved in an extramarital sexual alliance, a cause for divorce. Under these circumstances, breast feeding can be considered to be a litmus test, so to speak, of a woman's fidelity and chastity. It is also proof of the child's paternity (Cosminsky et al., 1993).

Comparable experiences have been found in Tanzania and Zambia. Very few women in Tanzania who have tested positive for HIV disclosed their status to their husbands because they feared abandonment. Several who did were divorced (Temmerman, 1992). Among the Tonga of Southern Zambia, AIDS has been incorporated into an traditional disease, change, which is said to be caused by sex with a woman who has miscarried. This is tantamount to contracting AIDS through sexual pollution (Mogensen, 1995).

Specific practices of infant feeding may be associated with the social status, roles and responsibilities of mothers that must be fulfilled by women in many societies. For example, Ghanians define health, not simply as an absence of disease, as in the West, but the well-being of the mind, body, and spirit (Lindenbaum & Locke, 1993). Health is expressed through a person's ability to optimally perform social roles and responsibilities. Thus, if an HIV-infected Ghanaian women decide to formula feed, her decision may cause her to be negatively perceived by her family and friends. This is because she is not fulfilling her role as mother and, by having to purchase formula, may create an economic hardship for her family.

The discussion so far has raised important issues about women's status, relative power to make and adhere to independent decisions, and rules that govern the care and maintenance of infants and children. The literature has shown that not breast feeding an infant can be a marker of unacceptable and potentially punishable behavior. Divorce, violence, isolation and ostracism curtails or eliminates a woman's access to her kin and social networks, crucial for the survival for poor

women and their children (Sevgi & Holmes, 1990). The implications of women's complex reproductive responsibilities requires that a number of infant feeding choices be offered that will enable those with HIV infections to enhance their ability to respond to their varied situations.

Controversy over Infant Feeding Practices of HIV-Infected Women

Years of successful work to protect, support, and promote breast feeding and stem the spread of commercial breast milk substitutes is now threatened because of the concern about HIV transmission in breast milk (Latham, 1997). Inadequate sanitation, unsafe and scarce water supplies, no refrigeration, the temptation to dilute formula with water and other liquids, poor health services and little knowledge of hygiene are the conditions in which most Third World mothers live. They are prime conditions for formula-induced infant morbidity and mortality. The beneficial effects of breast feeding on diarrheal morbidity and mortality, on infant nutrition and health (protection against chronic ear and respiratory infections including pneumonia), and the spacing of births through lactational amenorrhea have been well documented and widely reviewed (Feachem & Koblinsky, 1989).

The literature suggests that exclusive breast feeding produces greater reduction in morbidity and mortality than partial breast feeding (Victoria et al., 1987). Cesar reports a nested case control study comparing 152 infants admitted to hospital and diagnosed by referees to have had pneumonia and 2391 population based controls (Cesar, 1999). From that study, it was concluded that breast feeding protected infants against pneumonia -- a leading cause of death in young children in the developing world.

Lessons learned about Infant Feeding of HIV-Infected Women

- Utilize participatory research to build upon women's knowledge and experience with the care and feeding of infants;
- Seek to reinforce women's positive attitudes and patterns of infant feeding;
- Learn about the attitudes toward breastfeeding and the implications of not breast feeding for both the woman and her baby;
- Recognize the impact of formula feeding on the health of the baby, the economic conditions of the family, the social impact on the mother, including the spacing of births, as well as the effect on the community, such as other mothers (HIV infected or not);
- Research the attitudes toward and use of options such as wet nursing, expressing breast milk, and milk banks, as well as culturally appropriate ways of caring for sick babies;
- Determine who makes the decision to breast feed or use supplements and the impact of ignoring these social norms.
- Understand that HIV related decisions are embedded in complex causal connections of hierarchy, interdependence, exchange, and well-being of the family, the household, and the community in which she lives.

Medical Questions that Remain Unanswered

The infant feeding controversy is complicated because the relevant medical data required to conduct a careful analysis remains unanswered or controversial (Linkages, 1998). This includes:

1. What are the precise risks of HIV transmission through breastfeeding? How do you compare these with the risks of morbidity and mortality from not breast feeding or/and following different alternative feeding options? How does the risk vary among various developing country settings?

2. What factors related to the mother, the infant, and the composition of breastmilk affect the risk of HIV infection through breastfeeding? With a high risk approach, the ability to predict individual outcomes over any length of time is quite limited. For example, if a women is infected with the HIV virus, approximately 20% (approximately 1 in 5) of the newborns are at risk and approximately 14 percent will be infected through breast feeding or 2.8%. Under optimal conditions, the infant's chances of survival are greater if fed artificially. However, in developing countries alternatives to breastfeeding are neither affordable nor safe in the 50 poorest countries where the infant mortality averages over 100 deaths per thousand live births, artificial feedings roughly triples the risk of infant death (Ibid.).

3. Is there an optimal period of breastfeeding (timing of weaning) that will maximize the benefits of breastfeeding while minimizing the risk of HIV transmission? How does this optimal period vary with circumstances? (Preble & Piwoz, 1998). Determining the timing of transmission during the initial weeks of life is critical to determining the exact risks of transmission through breastfeeding. The ability to determine the mode of infection at this age remains one of the major constraints to furthering our understanding of the HIV and breastfeeding relationship.

4. Does a woman's nutritional status affect transmission through breastmilk? (Latham, 1999).

Discordant information sometimes leads to denial, and rejection or is restated by the outside professionals who have planned simple solutions and decisions (Chambers, 1997) The more we know, however, the more complex must the thinking and planning be to devise solutions. It is easy to act under time and funding pressure, as the Philippines reforestation project has shown. However, scaling up too fast can result in unanticipated secondary consequences. The challenge is to utilize a participatory approach that will result in culturally appropriate, low-cost ways to reduce the risk of maternal-infant HIV transmission. The strategy attempts to prevent a decline in an already subordinate position of women and an increase in morbidity in the babies of women who are not infected with HIV.

Latham has proposed testing the following six alternatives for cultural acceptability and appropriateness for mothers living in different settings l) routine breast feeding, including six moths of exclusive breast feeding; 2) modified breast feeding; 3) heat treatment of expressed breast milk to kill the virus; 4) wet nursing; 5) donation (or even sales) of breast milk; 6) use of animal milks of homemade formulas; and 7) restricted to optimum conditions, formula feeding with no breast feeding (Latham, 1997, 1999). Separating formula feeding from the HIV clinical interventions would substantially diminish the potential influence of formula feeding on other mothers in

communities with large numbers of HIV infected women who are being provided with free formula to fed their infants. The above alternatives would support the WHO/UNICEF Code of Marketing of Breastmilk Substitutes.

The Cultural Context of Illness and Disease: Implications for Counseling and Building Community Support

Disease is not only experienced in the body of an individual. It is experienced in "time, place, history, and the context of a particular social world" (Good, 1997). Therefore, counseling pregnant women who are at risk for HIV infection is a complex and emotionally laden task. The counselor must not only be knowledgeable and skillful, but is sensitive to the individual woman as well as the social and cultural forces that exist in her client's community.

<u>Support from Significant Others and Peers</u>

The benefits of social supports have been demonstrated in the literature review. Yet, little is written about counseling partners and significant others to increase their support. A study in Egypt evaluated the effects of husbands' involvement in their wives' post abortion recovery and the use of contraceptives. The emotional and family planning support given by the husbands of patients was associated with improved post abortion outcomes, i.e., a faster emotional and physical recovery (Abdel-Tawab et. al, 1999). It was concluded that, when husbands received intense counseling by senior or well trained staff, they were more likely to support their wives and improve the post abortion outcomes as compared with men who were not involved in counseling. This suggests that contributing factors to the success of the counseling may have been related to both the level of skill of the counselors and the husband's positive perception of their counselor's status and position. Finally, administrative and logistic changes may be required to make counseling of significant others confidential, feasible and effective.

<u>Peers as Counselors:</u> The success of peer counselors versus professionals in resource-poor countries has been described in the literature. Findings suggest that those planning social interventions with counseling as a component must identify the critical characteristics of the counselors in their project. Under certain circumstances, when the topic is sensitive, individuals may not want to reveal personal issues to an individual who has direct or even indirect ties to their community or culture as illustrated in the discussion of traditional healers. This can also be true when the information provided by the client regarding behavior is in conflict with the cultural norms and values. At the same time, the literature has highlighted NGO projects that carefully, over time, engaged women in dialogues about confidential problems that resulted in suggested activities to solve them. NGO staff provided timely and sustained support of these actions.

<u>Professionals as Counselors:</u> However, few studies have examined the critical role of beliefs, attitudes, intentions, and behaviors of counselors working with HIV-infected mothers. For example, in one study, researchers found that some health providers appear to have a negative attitude and lack empathy for their clients (Linkages, 1999). Indigenous health providers, as well as Western-trained health workers, may share attitudes, values and norms of the communities in which they practice. In a previously cited study, training was provided to midwives who held

punitive attitudes towards women who both induced and spontaneously aborted (Billings, 1999). Many programs attempt to change attitudes by presenting information. That is only effective when attitudes are predicated on a lack of knowledge, which is not always the case. Attitudes are often deeply rooted in experience, norms and values and are difficult, and require a long time, to change. Alternatively, sometimes individuals from similar backgrounds, trained to conduct counseling are afraid to counsel on these issues or are ineffective because they over-identify with the woman. Therefore, counselors who are either professional or are of a higher status than the woman, her partners or her family in some circumstances may be more effective.

Criteria for selecting Counselors: Factors that influence that decision include 1) the recipients view of the role, status, and position of a helper, 2) their positive and negative attitudes toward medical and professional communities, 3) their concerns about confidentiality, the skill and knowledge required conduct counseling responsibly, 4) the amount and quality of counseling training, coaching, and consultation available, and 5) the availability of individuals available to fill positions. On the other hand, counselors, regardless of whether they are peers or professionals, must have, or be willing to acquire, the necessary knowledge, skills, and affective behaviors that will make them effective in complex and emotionally laden situations. Those who are planning counseling interventions must carefully consider these criteria.

Guidelines for Counseling

- First, the woman must be helped to make a decision about whether to take an HIV test.
- If the test is positive, she must decide whether to accept AZT treatment.
- The HIV-infected mother most likely fears losing her financial and social supports as well as fears a rapid decline in her health and her imminent death.
- Now ,he is being asked to decide on a feeding pattern so as not to infect her infant, a decision that may not be her decision alone.
- The decision-making process is further complicated by the fact that, in many instances, infant feeding options are far from simple decisions and, as has been pointed out, medical knowledge to help make those decision can be contradictory or unavailable.

Given the findings from the literature review, counselors must intervene based upon an understanding of the woman’s prescribed role, including the degree to which she has the authority to make certain choices. Her options are often narrowly defined because of the low status and position she has in her community and because of her experience and knowledge of feeding and care of infants. On the basis of her HIV status, as well as by making the wrong choice as to how to feed her infant, the woman may be subjected to stigmatism, ostracism, divorced, and/or experiences physical abuse. Given her emotional state and the multiple and complex social and cultural factors, helping a woman make the best decision for her and her infant is a daunting task for a counselor.

During counseling, culturally appropriate alternate infant feeding approaches such as wet nursing, expressing milk, etc. should be discussed. If after counseling, the mother chooses not to breast-fed, she should receive full information and instructions on procedures related to the alternative approach she has selected. If it is formula, she must receive information on, and adequate replacement feeding for, the child for up to two years of age and guidelines on breast care, until lactation stops. In cultures where this is appropriate, a discussion should be held regarding the

negative effects of adding supplements (laxative, glucose mixtures, appetite stimulants, etc.) into the formula. Mothers who choose to breast-fed should be advised of the possible increased transmission risk in the presence of cracked nipples, mastitis, and breast abscess or of oral lesions in the child. She should be taught how to prevent such problems through adequate breastfeeding techniques. A discussion should be held about the possibility of reducing the duration of breastfeeding as a way of reducing the risk of transmission where this can be achieved safely. The mother should be counseled on the need for follow-up health care for herself and her child Contraceptive advice should be given and, if she consents, early arrangements made to start with an appropriate method. Contraceptive advice is particularly important if she chooses not to breast-feed because of the loss of the contraceptive properties of breastfeeding. Based upon the information she is given, informed consent means that she must freely and voluntarily make a decisions about infant feeding and the use of contraceptives that is the best choice for her, given all the information available. It would be beneficial if counselors and/or the program staff work with mothers from the same community so that the mothers can provide support for one another. Social networks and social support have been demonstrated to be critical for women seeking reproductive health care (Rips, 1997).

<u>How to Counsel:</u> Given the need to identify, assess, train, and supervise counselors, a number of approaches have been proposed that may be beneficial. One approach is to apply the Freire approach to individual counseling (Wallerstein & Bernstein, 1988). Here, counselors are viewed as health educators who contribute information after individuals raise their themes for mutual reflection. Rather than imposing their own cultural values, counselors enter into authentic dialogues so that individuals emerge from their cultural silence and self-blame to redefine their own social reality. It has been found that women place great faith in the experiential knowledge that others with the disease have acquired, suggesting the role for peer counselors to educate women about treatment options and help develop community and peer support groups.

This model encourages a woman to develop her own action plans that address the problem of infant feeding relevant to her own life. Thus, the counselor must listen to understand the felt issues or themes, have a participatory dialogue about the HIV-infection and infant feeding, and then determine action or the positive changes that she has envisioned during their dialogue. Utilizing such an approach requires careful and extensive training.

Community support

Another program with potential application is one that was used to train community based health educators and lay activists in support of STD and HIV/AIDS programs (Schoepf, 1999) Many exercises were developed and tested by African anthropologists, physicians, health workers, sex workers and community leaders. Materials were piloted in the Democratic Republic of the Congo, Tanzania, Zambia, Uganda and Mali and the Ivory Coast. They are drawn from a variety of everyday situations and posed problems, stimulated reflection and allowed participants to practice in support of sexual behavior change. A variety of techniques were used, including case studies, sketches, role plays, drawings, and proverbs. Trainers provided opportunities for participants to practice the method and to generate new knowledge. Small group dynamics were employed in workshops to examine attitudes and impart difficult new concepts. Exercises that struck the

participants imaginations and built on existing knowledge helped them to retain and transfer new knowledge to others.

An essential part of a successful social intervention is building community support because vulnerability may not only refer to individuals, but to families and communities (Moser, 1993). Another useful approach is the Stepping Stone method, which uses techniques that promote open, dynamic and innovative ways to reflect on issues and take action. In Uganda it was successfully used to educate and mobilize communities and minimize their risk of becoming infected with AIDS (Welbourn, 1998). Similar approaches have been effective with village groups or women's organizations. The Indian Rural Support Program organized one such project around the problem of women's workload (Bilgi,1998). Through an interactive process, men began to recognize that women held multiple and difficult roles, which formerly men had ignored or denied. For purposes of the Glaxo Positive Action Programme, it is critical that community education be provided and support be mobilized for new mothers who are infected with HIV and community wide education and support for other mothers about the importance of breastfeeding to prevent illness and death in infants.

A Method of Analysis for Planners and Program Staff: Force Field Analysis

The Force Field Analysis is a method that planners and program staff can use to analyze the broad social and cultural situation in which an intervention is to be undertaken (Deutsch, 1968; Lewin, 1948). This approach will enable them to assess, in advance, how likely a project will be able to reach its goal. This analysis is a multi-staged approach process that can incorporate social, cultural and medical knowledge and understandings. As part of the initial analysis, a list of forces for and against reaching the goal is generated. See Table 2 below. While it initially may appear one column has more forces than the other, one must also analyze the strength of each force. Thus, three forces that are very strong are likely to be more potent forces than five forces that are weak. The strength of a force is determine by how important it is in relation to meeting the goal and how much it contributes to the success of the project.

It is possible to change the constellation of forces by adding or strengthening positive forces or removing, weakening, isolating, and/or compartmentalizing negative forces. However, every change in balance of forces will have side effects or secondary gains. The side effects of the rice irrigation and clay core village dam projects in Ghana have been described. The new surgical procedure developed to correct congenital hip disorders among the Navajo as a result of social knowledge has also been described. The following are examples that do not describe side effects and secondary gains. However, in conducting a force field analysis, it is important for planners to consider the results of their interventions.

Table 2: Force Field Analysis

Forces ***FOR*** the social intervention	Forces ***AGAINST*** the social intervention
1. Free formula 2. The sex, a boy baby 3. Knowledge of the benefits of alternative feeding patterns for infants of HIV infected women 4. Groups available who would be willing to help improve sanitation 5. Women acceptable to the mother and her family agree to wet nurse. 6. Presence of Support groups 7. Appropriate and individualized counseling 8. IEC 10. Other HIV infected women with infants 11. Will cause HIV infection in 30% of infants 12. Sufficient critical mass of HIV infected women who might be enabled and sustained to support each other (peer support)	1. Cost of formula feeding and access over time. 2. Stigma, social isolation, divorce, violence against mother who will be identified by her family and the community as infected with HIV/AIDS 3. Knowledge that she has the potential for producing a healthy baby at a future time 4. The sex, a girl baby 5. No support group 6. Rule-governed patterns of infant feeding including strong norms in support of breastfeeding 7. Status and responsibilities as a mother 8. Child will eventually be orphaned -- no interventions planned for this 9. Healers and others may identify woman as the cause of HIV 10. Tradition of mixing infant formula with other substances will produce illness 11. Inadequate sanitation, unsafe and scarce water supplies, and no refrigeration will contribute to morbidity and mortality 12. The potential that the formula would be consumed by the other children 13. Lactational amenhorrea will be lost 14. Morbidity and possibly mortality as a result of not breastfeeding 15. Decisions to discontinue breast feeding made by significant others not mother 16. Low status and limited autonomy of women in society 17. Attitudes towards outsiders blaming and attempting to change cultural norms regarding sexuality, etc. 18. Women who do not have HIV to feed their infants formula 96 with potentially increased infant morbidity and mortality 19. Insufficient data regarding the intervention, e.g., breastfeeding will not infect 70% of infants.

In Table 3, above, the forces **for** and those **against** change are listed. Some forces are provided only as examples and may be inappropriate for a particular culture and contain serious side effects as all forces do. The side effects of forces must always be weighted to determine if adding the force to the field would be useful for the assessment. Some forces listed have emerged from the review of the literature, such as incomplete or unknown data as a force **against** change, exemplified in the Pakistan reforestation project that focused on farmers with large farms rather approaching those with small farms who were more amenable to the change process. Another force **against** the change is the culturally inappropriate push to have the woman agree to formula feed even though it is not her decision but that of her mother-in-law and/or husband.

A force for positive support of HIV infected women would be other HIV infected women with infants in the community that can support one another as occurred in the WDP's anti-violence project in India. They built a coalition of women to pressure for change in areas important to them. The negative force labeled incomplete or unknown data may be moderate in strength, if much of the data can be obtained relatively easily. However, if it is difficult to obtain the data and that data is important to the project than it may be seen as a relatively strong and negative force. As data is collected in the second phase of the analysis, that data may be added as a force to either or both columns. So, for example, if data were generated that some individuals would serve as wet nurses for the HIV infected women and that the community supports wet nursing, then that would add more positive forces to that column. If the findings were mixed that forces would be added to both columns, that is, some people would volunteer to be wet nurses (positive) and some people do not support wet nursing (negative).

As pointed out in the literature review, when one intervenes, applying forces can result in side effects as well as secondary gains. The strong negative force in India for female infanticide was the desire to have only male children. As a side of effect of eliminating this practice, the number of unwanted female children born may increase. One way to minimize this as a negative force would be to build an orphanage for them. However, a critical factor in the success of the community wide project was providing alternative economic opportunities for the midwives that reduced their need to rely on infanticide to obtain income. This example recommends a complex and multifactorial intervention to assist women who are infected with HIV and their infants.

Planners and implementers must consider intervening with the children of infected mothers who very likely will be orphaned. If one is analyzing the intervention responsibly, then unanticipated and secondary effects must be addressed. If that force cannot be neutralized, compartmentalized, isolated or removed completely, than it is likely that this factor will contribute greatly to the ineffectiveness of the project. By compartmentalizing, one takes a negative force and surrounds it so that its effect is neutralized. For example, a concern is that, if HIV-infected mothers formula feed their infants, it will encourage other mothers to imitate her (a negative force). The negative secondary effect on non-HIV infected women who might be influenced to utilize formula rather than breast-fed their infants must be incorporated into planning's analysis and response to the intervention. Counterbalancing that force would be an educational and support programs for all women in a community to reinforce the benefits of breastfeeding to themselves, their infants, and their families. The force field analysis closely coheres with the accumulated experiences of participatory approaches described in the literature review. A broadening and deepening of the proposed agenda is required to meet the challenge of the profound, uncertain, and complex problems for HIV infected women and their newborns in Africa and Asia.

Concluding Remarks

This chapter has described conceptual approaches and the historical background of interventions in local communities as a basis for planning for a multifaceted interventions to support for HIV infected women and their infants, their families and communities. We have also sought to raise fundamental questions that provide the context for such planning through specific cases presented in the paper. We tried to bring into relief the integral relationship between poverty, gender inequality, social and cultural norms, HIV infection and infant care and feeding.

Over the past several decades, the high cost of addressing public health problems has resulted in the development of a number of overall strategies designed to plan community-based interventions. One strategy is the "high risk" approach. Developed on the basis of retrospective data, the assumption is that a relatively small number of families produce a majority of health problems in the community. If scarce resources are concentrated on this group, it is believed that it will result in "the biggest bang for the buck" (Chamberlain, 1984). Proponents of this approach can point to studies that show a higher than average incidence of specific problems coming from these high-risk groups and interventions that has benefited them. The attempt to provide short term AZT to HIV infected mothers and to encourage them to use formula feeding is one such effort.

The problem with this approach becomes apparent when one reviews similar attempts to apply this TOT-like approach to this social intervention. For example, epidemiologist may argue that, in resource poor countries, the health risks of MTCT are outweighed by the mortality risk to children who are breast-feeding. This type of "risk assessment" places HIV infected mothers in highly vulnerable positions in their community, and does not insure that the infant will survive, does not address that if they do because they may be orphaned. Furthermore, a woman's perception of her ability to breastfeed or to use alternatives may not be based on static, fixed measurements of the outcomes of infant health. It may be related to vulnerability that is integrally related to "complex aspects of well being and livelihood security that includes survival, security and self-respect" (Chambers, 1989a). Planners and implementers may also be ignoring HIV infected women's perception of risk that in fact may lead her to continue to have children, despite the diagnosis. The

potential to erode years of education and support for exclusive breastfeeding for mothers in resource poor communities is also ignored or neglected.

The risk/benefit analysis that emerges from a Western mode of thinking, is economically based, and usually does not consider the individuals who are the targets of the analysis and the particular aspects of the culture to which it is applied. An assumption is that it can be developed without the participation of community members. The critical question that is raised is: Who establishes the criteria for the cost/benefit analysis? For example, benefits may be perceived very differently for community members than for professionals. The perception of contraception of health and family planning officials can widely differ from community women. Professionals often apply the terms risk and safety to the likelihood of pregnancy associated with contraceptive failure--women may apply risk and safety to experienced side-effects and beliefs about the long term effects of particular contraception on their health. Can one assume to have a successful intervention, if it is predicated on assumptions that do not match those of the community in which the intervention is to occur?

The effects of planning and implementing a community intervention program are complicated. Many critical factors and program components need to be identified and managed. This paper has attempted to identify critical learning from past studies, to set forth the controversy related directly to infant feeding practices, to present issues that address the support of HIV infected women who find themselves and their infants in highly emotional and complex situations. In the paper, a method for planning and intervening is presented for analyzing the issues in a holistic manner.

Projects that are designed to address critical and complex social problems demand that change agents/professionals/planners act responsibly. Those intervening must understand the full range of issues and choose whether to intervene or not on the basis of a careful and thoughtful analysis of the potential outcomes. The neglect of the differences in the social-cultural context, in which interventions are planned, does not identify potential constraints, nor can it design appropriate ways to increase individual, family and community's capabilities. HIV/AIDS, like sexuality, must be considered within its local social contexts. Responses, therefore, must vary along cultural lines not the global (Model T) variety. This paper recommends working with NGOs who can conduct assessments and engage in meaningful dialogues with community participants that lead to the design of culturally appropriate and varied interventions that meet the needs of different women living in diverse situations. More time and resources to sustain and support the intervention may be required to build such community capacity, but the effects can last beyond the time frame of the program. The benefits to mothers, their families, and the communities, in which they live, however, are potentially great.

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