# Implementing Freirean Perspectives in HIV-AIDS Education among Preliterate Guatemalan Maya Immigrants

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The focus of this study was on a HIV-AIDS education project undertaken as a facet of a broader Family Literacy Program (FLP), implemented within a Guatemalan Maya immigrant community in south Florida. Project participants had typically experienced between 0-3 years of formal education in their home countries, had limited reading and writing skills in any language, and lived in an area designated by Public Health Agencies as an HIV-AIDS "hot zone" where the spread of the disease was unusually high (Barton, 2004). The Maya were typically not included in County Public Health statistics, which were limited to the categories of White, Black, and Latino, thereby making the Maya publicly invisible in this crisis, even though they were, perhaps, the most vulnerable population.

This article is based on two years of action research conducted in the context of the HIV-AIDS education project. The project was spearheaded by an HIV-AIDS educator (referred to as "the project educator" in this article) who had been trained and certified by the American Red Cross and the State and County Departments of Public Health. She was supported by the Director (referred to as "the director" in this article) of the Family Literacy Program that had operated within the community for the past 13 years. (Both of them will be referred to as "the educators" in this article.) The project, still in operation, consists of a series of instructional sessions developed from American Red Cross materials but adapted, through extensive research, to address the cultural back-

grounds of the diverse audiences which, in the first two years, totaled 1,424 participants. This is the first of multiple studies surrounding this program. As such, it was guided by the following questions that were intentionally broad-based, exploratory and descriptive in nature.

- (1) What were the unique challenges of implementing an HIV-AIDS education project within this community?
- (2) How were those challenges addressed?
- (3) To what extent did a Freirean perspective on education contribute to the project's effectiveness?

It must be noted that the term "challenges" used in this article refers not to impediments or obstacles, but rather to factors or realities that prevented a "business as usual" approach to program implementation. As such, a challenge served as an impetus to engage in creativity and adaptability.

### Theoretical Framework

This study drew on three interrelated theoretical perspectives in its examination of the implementation of the HIV-AIDS education project: a Freirean perspective of literacy development (Freire, 1996; Freire & Macedo, 1987), a sociological perspective of health (Wermuth, 2003), and critical action research (Carr & Kemmis, 1986; Kemmis & McTaggart, 2000). The project was based on materials provided by the American Red Cross that explicitly advocated (in its instructor training materials) a dialogic approach to instruction, underscoring the urgency for effective education through the engagement of participants. A movement away from a traditional "banking" approach that typically alienates students to one that would draw on the experiences and concerns of the participants also necessitated an in-depth understanding of the culture(s) of the target population. In order to "situate the educational event—curriculum, process and product—within the lives and culture of people attaining the literacy" (Purcell-Gates & Waterman, 2000, p. 11), the first six months of this action research project were devoted to the project educator's own education as she conducted research on the community, the culture of the people, their sociocultural needs and realities, and the culture(s) and politics of Guatemala. This laid the groundwork for cultural authenticity/congruency in the manner and languages in which new ideas were presented; the venues for instructional sessions were also grounded in the reality of participants' lives and comfort zones.

The fact that most of the participants could not read or write, high-

lighted the importance of Freire's notion of "reading the world" prior to "reading the word" (Freire & Macedo, 1987). This was particularly pertinent because the HIV-AIDS education program functioned in conjunction with a Family Literacy Program whose funding agencies privileged the reading of the word, while the health agencies supporting HIV-AIDS education were more concerned with health literacy that would come through reading the world, in this case, the complex world of HIV-AIDS. "Reading the world is not preceded merely by reading the world, but by a certain form of *writing*, it or *re-writing* it, that is, of transforming it by means of conscious, practical work" (Freire & Macedo, 1987, p. 35).

The inability to rely on printed material required that the instructional sessions be rooted in the oral traditional, familiar to the Maya. Reliance on the oral was not merely a simplistic choice of medium of instruction: the entire ethos of the learning context needed to be re-considered to facilitate effective learning. Consequently, the effectiveness of such an educational program was not to be assessed through how much vocabulary and knowledge the participants had amassed on HIV-AIDS, but rather as a demonstration of such literacy in practice: specifically through changes in their lifestyles, attitudes, and choices. In this context, it mattered little that a participant knew the "right answers" to questions posed; rather it became crucial that their understanding be reflected in responsible life choices as spouses, parents and citizens.

This study also takes a sociological—rather than a purely biological—perspective of health and draws on the work of Wermuth (2003) who viewed health as a function of social inequality. In the case of this population, the inequalities brought on by the lack of educational opportunity (in Guatemala, as well as limited adult education opportunities in the U.S.), poverty and consequent lack of health care, each contributed to the increased vulnerability of this population to HIV-AIDS. Wermuth highlighted the need for critical/emancipatory health education as reflected in the 2002 World Health Report. "The health system…has the responsibility to try to reduce inequalities by preferentially improving the health of the worse off.... The objective of good health is really twofold: the best attainable average level—goodness—and the smallest, feasible differences among individuals and groups—fairness" (Wermuth, 2003, p. 1). This latter goal was central to this project.

The project derived its critical nature from its commitment to a community that had no access to health education due to language, cultural, and/or economic barriers, about a disease of which they were unaware. As action research, the program emerged from a problem of immediacy: the need for accessible and relevant education to members of the Guatemalan Maya population in order to prevent further rise in HIV-AIDS cases—and

deaths—among this community. Many of the members of this population had fled Guatemala to escape genocide. As Maya, they (as well as the instructors at the FLP) were aware of the history of genocide that had faced indigenous populations around the world. Furthermore, the AIDS crisis in the continent of Africa threatened and indeed had claimed lives in unprecedented proportions. Within this global context, for the educators involved in this project, the price and the legacy of doing nothing about HIV-AIDS education would be socially unconscionable.

The program's uniqueness derived from its situatedness in the lives and culture of the members of the community, and in its capacity to facilitate individual and social action to counter the spread of HIV-AIDS within a "pre-literate," poverty-stricken, multilingual immigrant community. As an example of critical action research, the design of the project as well as the sociocultural context of its implementation is central to this study.

# **Methods and Data Sources**

The work on this project has followed a spiral of self-reflective cycles of planning, acting, observing, and reflecting typical of action research projects (Kemmis & McTaggart, 2000). The initial six months were devoted to research on the target population and the community. This led to the designing and implementation of instructional sessions. Observation focused on gathering information on the project's effectiveness, and reflection after each session and at the end of each year, involved the identification of the bases for success or failure.

Gathered consistently over a period of two years, data sources included: community demographic information, participant observation of 61 educational presentations (25 in year 1; 36 in year 2; each 2-3 hours in length), field notes of the educators, focus group interviews with community facilitators, post-presentation reflections of participants, and individual interviews with facilitators and participants. Additional data pertinent to this article included: American Red Cross training and instructional materials, curriculum/presentation materials which were secular and scientifically driven, and reports of the program. These data were analyzed to identify the challenges of this educational undertaking, the manner in which these challenges were addressed and the indicators of success in these efforts. The results highlight insights that emerged through each cycle of the project.

## **Results**

### **Planning**

Several insights emerged during the ongoing planning of this project. Most emerged during the first six months that were devoted to the investigation of the community, but additional insights emerged through discussions with participants during the implementation of the project. Collectively, they revealed the uniqueness of the target population.

HIV-AIDS "hot spot." The project was precipitated by concerns from the State Department of Health that indicated that the state had the highest AIDS rates in the U.S., and that the project's target area fell within the part of the county that was ranked fifth in the nation with regard to the rate of AIDS cases per 100,000 people (National AIDS Treatment Advocacy Project, 2006). Within the county, 53% of all reported AIDS patients had died. The zip code within which the FLP was located was reported as having one of the highest rates of new HIV/AIDS cases in the year prior to the implementation of the project. This zip code also has the largest number of Guatemalan-born residents in the county, who represented 22 Maya languages. Furthermore, the city served as the "crossroads" for Guatemalan migration. Many groups broke journey here on their way to northern states or when visiting Guatemala. Unverified reports of a rise in AIDS in the rural areas in Guatemala from which these immigrants came (and frequently visited) added to the urgency for HIV-AIDS education in this community.

However, county statistics did not include the Maya as a separate category; they were included in the "Hispanic" section of the county's three category system of "White," "Black," and "Hispanic." Without the specific data related to this zip code, the threat to this community would not have been addressed. As the Director of the FLP noted in an interview with journalists about the county statistics, "This is very good news for the Maya community. No one is infected. How typical of Native American reality—ignored" (Barton, 2004).

Public Health clinicians had informed the FLP of an increase in HIV-AIDS diagnoses among the Maya immigrants and sought assistance in reaching this population. These diagnoses were typically made in the later stages of the disease, and patients were unaware of the existence of the disease. Prior to the project's implementation, the role of the FLP's staffwas to provide psychological and spiritual support to the victims and their families as they prepared for death, funerals and burials within a new culture and land. (Note: "land" is an important concept to the Maya

population; their intimate connection to their homeland added further grief to this process.)

AIDS as a "strange" disease. AIDS was not a disease that the forebears of this population knew; hence it posed a culturally alien experience. Knowledge passed down through generations by the Maya healers did not include HIV-AIDS. The disease thrust this group into a world that even their healers could not read. Adding to the complexity was the atypical nature of HIV-AIDS as an illness: you could be sick, but with no visible symptoms; when you did get sick you showed symptoms of a different disease such as pneumonia; alleviating the symptoms did not mean that the disease had been eradicated; although medicines prescribed were very expensive they did not cure the disease. Public discussions of sexual behavior necessitated by HIV-AIDS education, typically a private topic, posed an additional cultural barrier in the education efforts.

The Maya are not "Hispanics." One of the barriers facing the Maya in terms of access to community support is a misunderstanding of their cultural identity. The Maya are indigenous peoples. The group served by this project is predominantly from Guatemala. Contrary to prevalent mainstream assumptions, they are not Latinos or Hispanics, and Spanish is not their native tongue. Therefore, community services targeted towards Latinos and Spanish-speakers fail to include the Maya, who are consistently categorized as Hispanics. Twenty-two Maya languages have been registered among the residents in the county. Culturally, their rural and isolated lifestyles have made the Maya more removed from western culture and values; proud of an ancient heritage, they have been less prone to cultural change. However, gender roles included the value of "machismo" for men, where male infidelity was deemed normal and accepted by wives.

Literacy levels. This Maya community served by this project had experienced very limited formal schooling in Guatemala. For men, the mean number of years spent in school was three years, while for women served through the project the mean was less than a year. Consequently, many were unable to read or write in any language. Most would be classified as "pre-literate." This meant that HIV-AIDS education could not be based on written language.

*Poverty*. All participants in the project lived in poverty; consequently, few had access to healthcare. Poverty, illiteracy, and lack of health care set in motion a cycle of circumstances that prevented participants from access to public health education efforts (which relied on written language), early detection, medication, or counseling. Although some women had the opportunity for health education through public prenatal

health clinics, these sessions were conducted in English and participants were asked to bring their own translators.

### *Implementation*

The educational program consisted of multiple instructional presentations organized around a cluster of six topics. These topics included: What is HIV? Who is at risk? What are the risk factors? Myths and misconceptions about AIDS, Testing and Public Health services. Follow up sessions included related topics such as alcoholism (that could lead to risky behavior or be the result of HIV diagnosis), domestic violence (that arises in the context of infidelity or adolescent sexuality), peer pressure (especially with youth), cross cultural values and norms, and family communication. Although American Red Cross instructional materials were typically designed to include many topics in a single instructional session, the project sessions focused on fewer topics at a time. Consequently, participants attended multiple sessions during the course of the project. Highlighted in this section are key components of the HIV-AIDS educational program that were designed to address the factors identified in the planning cycle.

Multiple languages. Currently the instructional program represents five languages. While a bilingual/multilingual format is common, instruction is also offered to language-specific groups. To date, HIV-AIDS education has been offered in three Maya languages—Q'anjob'al, Mam, and Jakalteco—and in English and Spanish. It is important to note that despite the rise in the Latino population in the region, the primary educator of this project is the county's only Spanish-speaking person certified to provide HIV-AIDS education.

Community facilitators. A unique feature in the design of the educational project was the use of community facilitators as instructional leaders. These community facilitators are typically active members of community who have attended previous sessions (conducted in Spanish) and who are willing to present the information in a Maya language. They are trained by the project educator to lead discussions in the target language; however, the project educator is always present at every instructional presentation. Fourteen community facilitators have been trained to work with Q'anjob'al, Mam, and Jakalteco speakers and this has broadened the 'reach' of the program both linguistically and geographically (seven cities).

*Multiple formats*. Instruction included a variety of formats and audiences. The typical format was the team teaching approach where community facilitators led discussions, supported by the project educator

who was present to clarify information. The project educator typically facilitated Spanish language sessions. All sessions were dialogic in nature with the dialogue emerging from the presentation of a problem, either through a video, role-play, or a case study (presented orally in story format.) Community leaders, with the help of the project educator, would identify key points in the dialogue at which to introduce specific information such as the causes of HIV-AIDS, myths about AIDS, risk factors, or procedures for testing.

'Follow up' sessions were conducted in response to specific requests from participant groups who identified questions, topics, or audiences for the subsequent sessions. These requests sometimes yielded menonly or women-only sessions. Special sessions have been held for youth. Typically, however, the audience consisted of groups of families. The project educator has also met with couples and individuals to provide more private and specific discussions of concerns. More recently testing sessions, where groups of participants have undergone HIV-AIDS testing, were also conducted.

Multiple venues were used as well. Small group instruction was successful with sessions held in participants' homes where a small neighborhood was the specific target audience. Larger groups were accommodated at the premises of the FLP or at churches. Perhaps most unique has been the request for instruction in the open fields where migrant farmers work. The adaptability of the program to reach different audiences in diverse venues has been central to its 'reach' within the community.

Community setting. One of the key cultural values of the Guatemalan Maya population is its community-orientedness. This sense of community was included in the project in a variety of ways. Instructional sessions were designed less as "classes" and more as community gatherings, replete with food prepared by community members. The sharing of food and the presence of children (who often played in an adjoining room) enhanced the family-orientedness of the project. Venues were familiar and comfortable to participants. The comfort with the setting and the prior knowledge of other participants supported the dialogic approach. Unlike mainstream HIV-AIDS education which focuses on individual choice, this project focused on relationships and family well-being. The idea that it was more than the individual, but the family, that was impacted by an HIV diagnosis, and considerations of how one protected one's family from the disease emphasized this collective consciousness. The use of a video "Mi Hermano/My Brother" (American Red Cross, 1990) that featured a family torn apart by the AIDS-related death of a newly married son served to humanize the lessons to be learned (rather than treating it as a biological, socially disconnected phenomenon as it is in mainstream educational institutions) and provided a useful impetus for the discussion of a variety of social, psychological, biological and cultural issues.

Metaphors and symbols. The use of the poignant story of "Mi Hermano/My Brother" drew on the Maya tradition of oral story telling and the use of such stories for education and reflection. Additionally, the use of metaphors and symbols became a key instructional tool. Confronted in the planning stage by the fact that there was no equivalent Maya word for virus, and the fact that the virus was not visible and lay dormant for years without visible symptoms of disease, the educator drew on the participants' knowledge of farming to establish her point. The metaphor of the worm (unseen) eating at the root of a seemingly healthy plant emerged as an effective image consequently used by community facilitators as well. Drawing on the cultural significance of the community 'healer' she noted that a doctor could see this virus as she encouraged participants to get tested (typically a culturally alien experience.)

In order to explain the impact of HIV on the body's immune system (to a population that had never had a science class), the educator—drawing on the concept of street theater popular in Central American nations—used drama. Based on a script written by a Salvadoran, the players were (1) the human body, (2) a soldier who represented the immune system and functioned as a 'body guard' to the body, (3) germs encountered everyday, which the soldier fought and overcame, and (4) HIV in the form of a sexual partner of 'the human body' (player #1). The soldier battles against HIV but eventually succumbs; and the body eventually succumbs to everyday germs.

A culturally authentic symbol that emerged as powerful was the pregnant mother (typically there was one present in the room). Asking about the fate of her unborn child, especially in the context of the infidelity of her husband and the consequent roles and responsibilities of both partners towards their family, served to make HIV-AIDS education explicitly about them, rather than an externally imposed western-oriented set of ideas.

### **Observations**

What were the indicators that any of these efforts were having an impact? Included here are the educators' observations of the responses of participants to the education sessions.

Interest and engagement. One of the key indicators of the impact of the sessions has been the requests for more, which have been offered in multiple formats including opportunities to re-hear similar information and clarify questions, requests for similar discussions with different groups of neighbors, co-workers, and acquaintances, and additional topics and informal individual or family follow-up sessions. In fact, excluding the introductory instructional session, all others emerged through community networking and specific requests for such education. As such, the project offered instruction that was not externally imposed but actively requested by the participants.

Participant interest was also indicated by the number and type of questions asked in the instructional sessions. The emerging questions, which often shaped the planning of subsequent instructional sessions, reflected the impact of the information, the participants' obvious concern about HIV, and their understanding/internalization of the facts presented. Questions varied along gender lines. Men expressed interest in discussing the virus, its dormancy, testing, and alcoholism as it related to risk behaviors. These gender-specific questions included: I had a partner several years ago.... Might I be infected? How long does the virus lie dormant? How will I know if I have the virus? What do I need to do to be tested? While it appears that these questions were individually focused (as opposed to the women's concerns presented below), their form belies the men's reflections on their choices as men and as providers for the family.

Women's concerns centered on their children and ranged from the health of the unborn to the behaviors of the adolescents. "Will my baby be infected?" has emerged as an inevitable question among pregnant mothers. What about my other children? Might they be infected? Women consistently requested more sessions for the men of their community and this led to several gender-specific sessions. This concern is linked to male promiscuity and the machismo identity among men. Concerns about alcoholism, domestic violence, and rape led to follow up sessions on these topics as women began to identify the means by which they could be infected. The connections among women's concerns about men's infidelity, the tensions that arose as a result, and subsequent alcoholism and domestic violence, laid the groundwork for role plays in instructional sessions and led to the development of formal curriculum units in the FLP.

Increased community leadership. The Maya have a strong sense of social responsibility and this topic facilitated community leadership in a variety of ways. This included undertaking the role of community facilitator of a session, thereby enabling the project to reach language groups that otherwise would not have been impacted. These volunteers have ensured that participants receive HIV-AIDS education from a certified educator in their own language, the only option available in a four county region. Other examples of community leadership have emerged when participants have hosted sessions in their homes and have been the liaisons between the project staff and their neighborhoods in the

education effort. These leaders also identify community members who need education and accompany them for instruction. One of the most active community leaders represented an interesting example of Freire's distinction between reading the world and the word. She was also a long term participant in the FLP, and her progress according to the traditional benchmarks of literacy ('reading the word") was limited; yet her community involvement indicated a tremendous capacity to "read the world" as she not only recognized the significance of HIV-AIDS but engaged in advocacy for her family in her children's school and in the public health care system.

Emerging gender roles. An interesting outcome of these sessions was the emerging gender role development among both men and women. Although it was anticipated that men would be reluctant to give up their macho lifestyle, for many their choice in favor of monogamy and fidelity was linked to their culture-specific male role as protectors of the family. "Our grandfathers were faithful so they did not get sick." "As men, it is our duty to take care of our families. If we get sick we will be a burden on them. Our children will have fewer chances for success." Correspondingly, women began to make fidelity a requirement within their marriages and to consider the need to sever relationships with promiscuous men, in favor of protecting their children. "If he already has HIV, then I need to make sure that I am still alive for my children." Prior to these presentations, men and women accepted male promiscuity as a facet of the male identity.

Opting for testing. Perhaps the most significant indicator of the project's impact has been the choice of participants to be tested for HIV. Although this outcome is typically achieved after several sessions, participants have begun to request HIV/AIDS testing. A recent outcome was the testing of 40 participants in a single session; all of whom tested negative, a greater cause for celebration.

### Reflection

Reflection on the project occurred continually. Included in this section are insights that emerged through a reflection on the entire project, as a whole. Central to this reflection was the question: To what extent did the project's design, grounded in a Freirean approach to education, facilitate the observed outcomes of the project?

Education as humanizing. The entire project was built around a fundamental valuing of human life, which Freire (1996) labeled "biophily." Its opposite—"necrophily"—characterized by oppression and overwhelming control, was "nourished by love of death, not life" (p. 58). Pedagogy

thus conceptualized was "dedicated to the alleviation of human suffering" and prevented "students from being hurt" (Kincheloe, 2004, pp. 11 & 13). HIV-AIDS education conceptualized around the urgent need to protect lives and prevent death reflected the essence of education that was humanizing. Emerging from a reality where illiteracy about HIV-AIDS meant death, this program was developed as an urgent life saving mechanism within a community, where its absence would have resulted in a silent, self-inflicted genocide. Maya history is already marred by genocide. First, as indigenous peoples in the Americas they share a legacy of genocide with native populations. More recently, members of this group had fled genocide that grew out of political struggle in which the Maya became a target of warring factions. Today, in the context of the ravages of AIDS in the continent of Africa, the prevention of a third wave of genocide became an imperative, rather than a choice.

Education as dialogic. The use of community facilitators eliminated the 'expert/novice' dichotomy of traditional instruction and allowed for a more dialogic approach. In fact, it was the dialogic approach that supported the comfort level of facilitators, who would not have agreed to play a more didactic role. They did not see themselves as "experts" but rather as 'facilitators of dialogue' in the specific Maya language of their group. Their role was essential to the success of the program because without their language skills, these target populations would not have been reached. The "expert" on HIV/AIDS, replete with her "credentials" as a "trained" educator, took a less visible/vocal role in instructional settings, allowing her "expertise" to serve a clarifying function. The dialogic function of the instruction operated on a more macro level as well, as facilitators and participants identified topics and target audiences for future instructional sessions. It was through this process that youth-oriented sessions (recommended by concerned parents) and male-only sessions (recommended by male participants on behalf of their co-workers, or women on behalf of their husbands) were developed and implemented.

Cultural authenticity. This project was grounded in the lives of the participants. This "grounding" was initially achieved through the research efforts of the educator at the outset of the project. The project's validation of the participants' lives not only served to enhance understanding (through relevant metaphors and symbols), but also supported behavioral and attitudinal change free of any cross cultural tension. The valuing of women's roles as mothers and of men's roles as providers and protectors of their families provided relevance and significance to the information presented.

The flexibility of format and venue, including trips to fields for sessions with farm workers, maintained a connection with participants'

realities. In one of the first sessions in the field, the participant who requested the instruction was unable to provide the educator detailed directions to the site because of its remote nature. The educator was given partial directions to a particular intersection and had to be in cell phone contact with the organizer as she found her way to the open field, where she was hailed by the group of men waving their hands to flag her to her destination. Similarly, the hosting of sessions in participants' homes, where children were comfortable and food was shared, demonstrated the importance of adapting instruction to the realities of the participants' lives.

The grounding of the project in the lives of the participants also yielded insights about their lives, which contributed to the ongoing authenticity of the program, as well as to the identification of new concerns. An important insight learned was the vulnerability of single men, especially groups of single men who lived together isolated from other community members. For instance, men described how their supervisor "rewarded" their hard work at the end of the month by inviting prostitutes to their living quarters and encouraging them to "engage" in their "male urges." After realizing the risks that this behavior posed, some of the men worried about insulting their supervisors if they refused to participate in these "celebratory" activities. A related insight was the fact that the lack of recreational opportunities for these men limited their evening 'entertainment' to alcohol and sex, both risk factors for HIV.

Education as struggle. The health literacy provided through this project did not rely on reading and writing skills but focused on a broader perspective of literacy as practice. Participants' responses to the information, their requests for follow up sessions and subsequent actions (opting to be tested; behavior changes; attitudes towards fidelity) reflected their ability to "read" their "world" in the complex context of HIV-AIDS education. Despite the receptivity of participants, change in attitude and action has come slowly through multiple iterations of similar ideas. For instance, it took many iterations to convince participants that testing was important; it took multiple sessions over a period of a year for one woman to reconcile her perspectives of her husband "as a good man" with her knowledge of his promiscuity. Unlike with audiences more reliant on written information, repetition of information has been central to the learning of this group. This has allowed for the processing of ideas at the learners' preferred pace.

Perhaps most discouraging for the project is the realization that, after two years of this project, the proportion of HIV diagnoses in the zip code has not decreased. The realization that this program is only a "drop in the bucket" and that the challenges of the situation make the

educators feel like they are "swimming against the tide" also provides impetus for continued diligence in this undertaking.

Although this project did not address poverty or inequitable social structures, it provided an important educational opportunity to which participants would not otherwise have had access. This essay highlights the small victories and insights of HIV-AIDS educators who dared to venture where few others would go. This project ensured that poverty, literacy levels, language or cultural background would not be barriers or excuses in the educational effort.

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