## Teaching Taboo Topics Through Technology

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## 1 Introduction to Teaching about Taboo Topics

This chapter discusses the challenges of providing education about topics that are considered taboo but must be taught to protect public health and welfare. A conceptualization of taboos is presented, and various ways through which technology can enable one to address taboo subjects while respecting social and cultural norms and values is discussed. Drawing on theoretical and empirical literature, advantages and disadvantages of various information and communication technologies (ICT)¹ and other strategies for providing the requisite information and persuasion necessary to address taboo topics effectively are analyzed. Criteria are presented for evaluating the effectiveness of such educational campaigns and curricula. Following this, the procedures one should employ to develop appropriate messages for ICT are discussed, using a recent AIDS campaign—Interactive Teaching AIDS—as an exemplar. Interactive Teaching AIDS is an ICT-based application designed by the TeachAIDS² organization to provide evidence-based, culturally-appropriate HIV/AIDS prevention education to audiences for whom discussing topics related to sexual practices is considered taboo.

#### 1.1 Laws and Norms

Virtually all societies have formal rules of behavior, called laws, which are defined by the state and enforced by a formal governmental apparatus. Even in democratic societies aiming to maximize individual freedom, laws are enforced independent of whether the individual members of the society believe that the rules reflect extant value systems or not (Maine, 2004). Even the most unpopular laws must be enforced to ensure the legitimacy of the entire legal system (Weber, 1978).

All societies also have informal rules of behavior, called norms, which are defined by culture and traditions. While many norms are embodied in and enforced by laws, there are also norms that simply set expectations of behaviors. That is, norms are enforced by general societal pressure (sometimes in addition to that of the state) or the collective infliction of non-legal sanctions on deviants, those who disobey the norms, subjecting them to stigmatization, criticism, ostracism, or even non-state force (Posner, 2002).

In addition to the distinction between laws and norms, there is also an important distinction between positive versus negative laws and norms. Positive laws and norms prescribe behaviors that individuals are required or pressured to perform. For example, almost all nations have laws requiring children to attend at least some school, some nations have laws requiring military service, and a few legally compel voting. Similarly, there are negative laws and norms, defining what people must not do: murder is illegal in virtually all societies, theft is illegal in most societies, and gum chewing is banned in a few societies, for example. In democratic societies, laws are primarily negatively stated—anything that is not expressly forbidden is permitted—while in totalitarian societies, laws are often positively stated—and anything that is not expressly permitted may be forbidden. Societies also have positive norms which are not related to their laws: virtually all cultures encourage age-based rituals, many cultures have words that are supposed to be spoken to elders, and a few specify markers that should be placed on homes.

#### 1.2 Taboos

The focus of this research is on *taboos*—negative norms that involve actions, practices, or states that carry a strong social stigma<sup>3</sup>. The word *taboo* comes from the Tongan word *tabu* (Webster's Dictionary, 2003), for "forbidden" or "banned". Capitan Cook defined the notion of taboo during his third voyage around the

<sup>&</sup>lt;sup>1</sup> ICT is defined as any form of digital technology (e.g. Internet, personal computers, mobile devices and other wireless communications) that helps transmit and receive information and aid communications.

<sup>&</sup>lt;sup>2</sup> TeachAIDS (www.TeachAIDS.org) is a California-based nonprofit founded through Stanford University and operating world-wide.

<sup>&</sup>lt;sup>3</sup> According to Erving Gofman, the Greeks originated the term stigma and it can be defined as "an attribute that is deeply discrediting" (Goffman, 1963).

world (Allan & Burridge, 2006) and introduced it into English in 1784, through a publication accounting his trip to Tahiti (Thody, 1997).

Taboos are social prohibitions created over time. They depend on, and are reinforced by, communitywide complicity (Douglas, 2002). They are inextricably linked to culture and thus vary significantly across the world; what is taboo in one culture may be completely acceptable in another. Societies create taboos for a number of reasons, including:

<u>Supporting the Legal System.</u> Laws reflect individuals' covenants with the greater society. That is, to the extent that laws are legitimate, they reflect the society's norms. Thus, with few exceptions (e.g., driving a few miles over the speed limit), violating the law is a taboo in all societies. The stronger the norm in which a law is grounded (e.g., murder vs. copyright violations), the greater the taboo against violating that law.

Supporting Religion and Other Belief Systems. Religious prohibitions are often more strict than legal ones. While an activity may be legal, violating a prohibition of one's religion, particularly in very pious cultures, is taboo. Nearly every religion and culture has one or more foods or drinks that may not be consumed (sometimes under certain circumstances). For example, for Muslims, eating pork is taboo while eating beef is perfectly acceptable, while for many Hindus, the opposite is the case. However, in India, where Islam and Hinduism represent the vast majority of the people, neither is banned by law. In many cases, violating religious prohibitions can actually be considered more taboo than violating laws that prohibit such activities.

Relation to Other Taboos. In some cases, if an action or state is a direct consequence of, or related to, another taboo, then it becomes taboo by this association. Often, the taboo persists even if it is not actually related to the other taboo action or state. For example, the Old Testament forbids the eating of a calf in its mother's milk. This taboo has now been extended such that it is taboo for Orthodox Jews to eat any kind of meat in any kind of milk. Another example is the use of a wet nurse or milk-bank. Since wet nurses are allowable in cases where an HIV-positive mother wants to avoid passing the virus to her newborn, in some communities mothers that do not breastfeed may be thought to be seropositive. This exposes them to stigma associated with an HIV-infection (Population Reports, 2009). In areas where community members are aware of vertical transmission and breastfeeding is a cultural norm, a mother opting out of breastfeeding for any reason can lead to a taboo by association, even if it is not the reason she chose to forgo breastfeeding (Abiona, Onayade, Ijadunola, Obiajunwa, Aina & Thairu, 2006).

Protection Against Harm. A large number of taboos, arguably the vast majority, evolve from a need to protect against real or perceived harms. Laws against murder or drunk driving fall under this category. However, there are also taboos which have evolved within some groups to protect against harms which are not de jure illegal. Cigarette smoking, for example, is an activity which is generally legal, allowed by most religions, and unrelated to any other significant taboo. Nonetheless, a taboo against it has evolved in many sectors of society due to the fact that anyone in the smoker's immediate vicinity is subject to potential harm via second-hand inhalation of smoke. Some taboos are applied only to special categories of people. For example, some activities, words, and ideas are considered acceptable for adults but harmful to children, either because they are believed to adversely affect a child's development or threaten their "innocence." Thus, in the United States, the movie rating system identifies movies that might be taboo for children ("PG"), those that are particularly taboo for children under 13 ("PG-13"), and those which may not be seen by children under 17 ("NC-17"). Similarly, there are taboos with respect to minorities. These types of taboos most commonly apply to words and symbols which are considered offensive. The most extreme example of this is hate speech. Inciting hatred against a specific group is a form of speech which is illegal in Canada and numerous other countries, but is protected in the United States under the First Amendment of the U.S. Constitution. However, not only are negative characterizations of any minority group taboo in the United States; associating with individuals who make these characterizations is also considered taboo. Taboos that stem from the desire to protect against harm can take other forms as well. The desire to protect animals commonly kept as pets—e.g., dogs, cats, and horses—leads to taboos that make them inappropriate for consumption.

Because pets are often anthropomorphized to a certain extent by their owners, as well as by society at large, using these animals as food may feel to many groups "as if you are eating your own children" (Thody, 1997).

Reinforcement of Power Relations. In some cases, dominant persons or groups define certain topics or behaviors taboo as a way of controlling the actions of others in a population. Just as Newspeak in George Orwell's Nineteen Eighty-Four eradicated dangerous ideas by eliminating certain words from a language, so too may some individuals or groups be oppressed or controlled by making certain topics forbidden. Leading members of society and controllers of opinion have the power and influence to make taboos as repressive as they would like them to be (Douglas, 2002). In such cases, criticism is punished or suppressed, and entire topics may become unspeakable and unthinkable (Douglas, 2002). In China, for example, the government takes an active role in censoring not only information, but also certain topics of discussion: Internet searches on terms such as "freedom," "democracy," and "Falun Gong" consistently turn up no results, as these concepts are actively filtered from search engines (Kurtenbach, 2005; Thompson, 2006). What is particularly striking about the Chinese example of censorship is that individual members of society not only play a key role in preventing access to this information, they are openly proud of the fact that they are protecting their society (Thompson, 2006). In many parts of the world, certain power relations have become institutionalized as part of the culture. Criticism of these power relations, or activities which could lead to their criticism or erosion, are often considered taboo. One example is the historical relationship between monarchs in numerous European nations and their countries' citizens. The doctrine of royal absolutism, once common in many nations, dictated that a monarch's word and judgment were beyond contestation. While this took on religious overtones and justifications, this was ultimately a belief system designed to reinforce the power of monarchs over their subjects. While the taboos against criticizing monarchs might have been strong, the taboos concerning actions against monarchs were obviously much stronger. In most countries in the world, crimes of treason still carry some of harshest penalties, and these originate historically from crimes against monarchs themselves. Another example of taboos concerning power relationships is found in the caste system in India. It has traditionally been verboten (and in many circles, still is) for individuals of different castes to intermarry. As with other taboos in this category, while there are protections against harm which provide the ostensible justification for the existence of these taboos, the real origin of the taboo is the preservation of pre-existing power relations. In the case of the caste system, wealth, education, and social status were stratified according to caste, and members of higher castes needed to intermarry in order to preserve that social order. As such, the taboo against marrying someone of a lower caste was much stronger than the taboo against marrying someone of a higher caste. Overall, these sorts of taboos are only discredited, ameliorated, or lifted when leading members of society choose to modify, enrich, or eliminate them (Douglas, 2002).

## 2 Challenges in Teaching about Taboo Topics

## 2.1 Comparing Teaching Difficulties

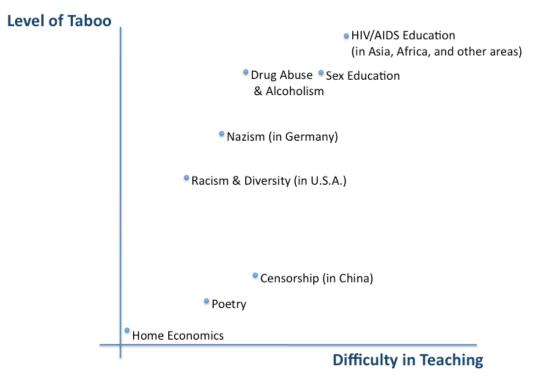
There are two broad categories in which one can place the vast majority of taboos: 1) taboos against actions or states (e.g., divorce, incest, cannibalism, food prohibitions, or trespassing, and 2) communication taboos, including taboos against words, symbols, and topics (e.g., profanity, swastikas, and sex education). The critical difference between action/state and communication taboos is that it is simple and straightforward to instruct individuals to not perform or assume taboo actions or states, or to discuss the efficacy and motivations for the existence of those taboos. However, by definition, it is extremely difficult or even impossible to directly express or discuss taboo words, symbols, or topics.

This difference becomes critical when taboos become unhelpful or anachronistic. For example, in the United States during the 1950s, the action of breastfeeding was taboo among the middle and upper classes because baby formula was viewed as more healthful. However, once there was scientific consensus that breastfeeding was healthier than formula for babies, through extensive deliberation, the previous norm could be discussed, evaluated, and overturned.

Conversely, openly discussing issues related to race and diversity can be extremely difficult, particularly in racially mixed settings (Benton & Daniel, 1996). In many schools and communities, which are comprised of diverse groups, teachers are encouraged to help students talk about their similarities and differences. However, determining the best mechanism to openly discuss such issues and further encourage students to feel safe and communicative remains a challenge for educators (Benton & Daniel, 1996). Some scholars argue that not talking about race at all—"artificial color-blindness" or being "colormute"— is just as harmful as discussing it in an inappropriate way (Benton & Daniel, 1996; Pollock, 2005). Teachers aim to foster comfortable and open environments in order to support a healthy exchange and communication of ideas, but communication taboos are extraordinarily difficult or impossible to even discuss, let alone overcome.

**Figure 1** below presents a set of taboo topics and the (arguable) relative level of difficulty in discussing them. This diagram was developed for illustrative purposes only in order to more easily discuss issues around teaching such topics. The location of the taboo topics will differ greatly based on time, culture, and contexts. However, the point remains that there are highly taboo topics and learning how to effectively teach about them, while respecting social and cultural norms and values, is critical.

Figure 1. Levels of Taboo for Various Topics vs. Difficulty in Teaching



<sup>\*</sup> The chart above is not to scale and is for illustrative purposes only.

Home Economics is a basic topic around the world, with few or no taboos associated with it. Hence, teaching it openly is straightforward. *Poetry* is somewhat different, as it is a broader category whose position may vary on the taboo scale based on its content; however, it too is not structurally difficult to teach.

*Censorship (in China)* may be relatively low on the taboo scale, in that people in China know that available information is censored, and many openly support this as a benevolent action by the government to protect its people. However, it may be difficult to teach fully about the concept and subject of censorship in China without being able to directly address which topics are censored and why.

The topic of *Racial Diversity* is taboo in many communities in the United States because of the country's history relating to slavery and civil rights, and the complex nature of race relations that have evolved over time.

Sex Education for youth, although not an illegal topic in most countries, is often still a taboo topic, of varying intensity. It is linked to premarital sex and premarital pregnancy, both of which often violate religious beliefs. The association of sex education to these other taboo topics elevates its position on the taboo scale. Many parents and teachers advocate abstinence-based education because they believe that comprehensive sex education promotes promiscuity among young people (Dhillon, 2006, Smith, Kippax, Aggleton & Tyrer, 2003), which they wish to discourage. Additionally, students may feel uncomfortable openly discussing sexrelated topics with their instructors, making the subject even more taboo. In order to enhance comfort during such lessons, some schools separate children by their gender or have outside organizations give specialized talks on these issues.

#### 2.1.1 Why is HIV/AIDS more difficult to teach about?

Educating a population on HIV/AIDS is in a somewhat different and arguably more challenging category than educating about other taboo topics. Most importantly, it may rank very high on the taboo scale, because it is a compound of many taboos. This makes it extremely difficult to teach in certain socially conservative contexts. Many Asian countries in particular historically tend to be socially conservative regarding topics relating to human sexuality. Comprehensive HIV/AIDS education in these countries generally requires teachers to discuss numerous sensitive and highly taboo topics that are associated with the transmission of HIV (e.g., premarital sex, adultery, commercial sex work, homosexuality, intravenous drug use, and death). One ministry official in Southeast Asia said the following with regards to teaching sex education in their schools:

"...sex education (or sexual education or sexuality education) in its liberal sense is not taught in any of the topics in the science syllabus developed by the Curriculum Development Department at any level of education in Brunei Darussalam as this is contrary to the teachings of Islam. Sex [education] that explicitly mentioned the encouragement] use of condoms and other forms of contraceptives including IUDs, sex enhancement devices and drugs including orally taken pills, masturbation, forms of intercourse (oral, anal, vaginal), 'free' sex, multiple partners, exchanging spouses, free intermingle among men and women for pleasure as a pastime, or communal marriage, polyandry, infidelity, the likes of any unnatural forms of sex (including homosexuality and lesbianism) is strongly condemned in Islam.

Unlawful and immoral sex practices including premarital sex are all forbidden (haram) in Islam. "(Smith, et. al., 2003)

The case of HIV/AIDS has been identified as "dual stigma"—not only is the syndrome itself stigmatized because it is perceived as a threat to health and safety, but, furthermore, it is associated with groups that were already highly stigmatized before the global outbreak (Herek & Glunt, 1988; Derlega & Barbee, 1998). In India, where homosexual acts were de jure illegal until the July 2009 ruling and commercial sex work is still de jure illegal, health care workers are in many cases unable to provide appropriate education on treatment and counseling to these groups at all (Agoramoorthy & Minna, 2007). Taboos relating to discussing issues like race can also come into play, since it is important to dispel misconceptions held by many people that certain groups are more susceptible to the disease. Hence, it is extremely difficult in many socially conservative societies to teach about HIV/AIDS prevention and treatment.

Finally, an unusual challenge in HIV/AIDS education is that even a presentation of the salient information may directly challenge social norms of power or gender relations. For example, the taboo concerning the

discussion of issues relating to gender power relations in many parts of the world is in this category. In societies where men are afforded more sexual freedom than women (which has historically been most societies in the world, though the extent varies considerably), confronting issues such as whether a husband is faithful, can be difficult to the point of being unacceptably offensive. To the degree that governments and public education systems allow the perpetuation of these taboos reinforcing such power relations, curricula, such as HIV/AIDS education materials, which challenge these social mores, may not be approved.

# 2.2 Previous and Existing Educational Approaches to Teaching about Taboo Topics

When a subject is too taboo or difficult to address, there is a strong temptation to avoid the subject entirely. When taboo topics are confronted, a range of pedagogical strategies have been employed:

Metaphors, Euphemisms and Humor—By employing specific metaphors, educators can illustrate a concept without directly mentioning the sensitive subject. Similarly, through euphemisms, educators may rely on subtle and, thus, less offensive expressions to communicate similar messages. It is often difficult to find metaphors or euphemisms that accurately communicate particular concepts clearly. Hence, the validation of the clarity, accuracy, and acceptability of these mechanisms within the target group is essential to their efficacy.

**Technical Terms**—Some curricula and/or educators utilize technical jargon in place of more commonplace words. This is a common technique to educate about sexuality or more generally the human body (e.g., using the words "myocardial infarction" instead of "heart attack"). The use of technical terminology may mask or distance the subject, making it more comfortable for both educators and learners to communicate about an issue. However, it may be unclear how well learners are able to understand, let alone absorb the materials.

**Direct Approach**—Some educators believe the best way to absolve a topic of its taboo status is to talk openly and directly about it, regardless of the resulting discomfort levels among participants. The assumption is that with open discussion, individuals will become more comfortable and, in time, the taboo will diminish or even cease to exist. However, this strategy is not viable when the taboo is reified through law.

**Localization**—Creating culturally-appropriate versions of curricula, which reflect the local context, is another way to appeal to individual communities. Although customization may be challenging, and in some situations more expensive, it may help learners to further identify with the particulars of a subject. Incorporating feedback from individuals who are familiar with the ground realities, rather than using a one-size-fits-all methodology, can make the materials more acceptable and comfortable for the learners.

Below are two examples that demonstrate the use of existing approaches to educating about taboo topics. Since research indicates that most taboos around the world are related to the human body and its various transformations (e.g., sexuality, disease and death) (Allan & Burridge, 2006), the examples selected below fall within this category. Furthermore, topics that are both taboo and relate to improving human health are especially important to address because they represent tremendous opportunities and challenges for the population; only through accurate education can individuals inform and protect themselves.

### 2.2.1 Existing Campaign Exemplars

#### **Example 1: Breast Cancer Education in Native American Communities**

There are significant public health efforts to educate women about breast cancer in the United States. Accurate and timely information is provided through multiple sources, including personal doctors, newspapers, magazines, and scholastic resources. However, open discussion about breast cancer is strictly

forbidden in certain Native American communities, significantly hindering early detection and appropriate treatment. In the Navajo language, the word "cancer" literally means "the sore that does not heal" and, therefore, conjures a sense of hopelessness, preventing early cancer detection in these communities. Furthermore, it is culturally taboo to talk about cancer because the community believes that to discuss cancer means to invite it (Robinson, Sandoval, Baldwin & Sanderson, 2005).

After being diagnosed with breast cancer, Nellie Sandoval, and her oncologist Frances Robinson, developed a nine-minute pilot informational video to present accurate and valuable information (e.g., early detection, self-examination) to more than 100 Native Americans across several states. To connect with the target population, the video was narrated by a Native American health healer and included a "message of permission" for learners to seek information and accept a new tribal tradition. In the pilot study, 100 percent of the respondents said they received information they needed. The success of the first video triggered the need for a second one based on breast cancer treatment modalities. Researchers associated with this project have plans to conduct a longitudinal study on the efficacy of the culturally-sensitive learning materials (Robinson et al., 2005).

#### Example 2: Maternal Health in Mali

As late as the 1990s, pregnancy was considered a taboo topic among certain communities in Mali and was rarely discussed even between husbands and wives. Couples associated issues relating to pregnancy and maternal health with shame and embarrassment (Clemmons & Coulibaly, 2000). The strong social prohibition made it difficult for women to receive the additional care and proper nutrition needed during pregnancy. Even in cases where women wanted to seek maternal health services, their emotions inhibited them from discussing such needs with their partners (Clemmons & Coulibaly, 2000). The lack of direct and open communication was a contributing factor to Mali suffering from one of the highest maternal and infant mortality rates in the world<sup>4</sup> (Singhal & Rogers, 2003).

In 1989, research through the Dioro Child Survival Project revealed the cultural and social barriers to women seeking maternal health services. Researchers built directly on Malian tradition to promote behavioral change. Traditionally, Malian married women wore a white cloth, called the *pendelu*, which symbolized marital roles and duties. The Dioro Project authorities used local *griots* (Malian educators who are also entertainers) to introduce a tacit cultural symbol to represent the change in status. The married Malian women were encouraged to wear a green pendelu (instead of the traditional white) when they became pregnant. Instantly, the people around the pregnant woman, including her husband, knew of her status and could support her appropriately, without any discussion needing to take place. This tacit symbol dramatically increased transparency, knowledge, and communication between husbands and wives while maintaining sensitivity to the context of cultural change. Three months after the campaign, survey results demonstrated that communication about maternal health rose from 3 percent to 65.5 percent among married couples (Clemmons & Coulibaly, 2000). Also, 41.7 percent of the husbands interviewed said they lightened their wife's workload during her pregnancy and 49.6 percent said they made sure she received good nutrition (Clemmons & Coulibaly, 2000).

The above examples employ different combinations of the techniques described earlier to teach about taboo topics as illustrated below:

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<sup>&</sup>lt;sup>4</sup> During this time in Mali, infant mortality (170 per 1000 live births) and maternal mortality (2000 per 100,000 live births) were extremely high (Fishman, Gottert, Kanté, Parlato, Anthony, 1998, as cited in Parlato & Seidel, 1998). For children between 3-36 months old, 11 percent showed signs of acute malnutrition and 25 percent for chronic malnutrition (National Demographic and Health Survey, 1987, as cited in Parlato & Seidel, 1998).

**Table 1. Techniques For Teaching About Taboo Topics** 

	Avoidance (Indirect Discourse)	Metaphors & Euphemism	Technical Terms	Direct Approach	Localization
Example 1: Breast Cancer Among Native Americans			X	X	Х
Example 2: Child and Maternal Health in Mali	X	X			Х

#### 2.3 Framework for Evaluation of Curricula Relating to Taboo Topics

Providing education materials is only the first step in the learning process. It is equally important to evaluate whether the learners are absorbing the target messages after the content has been delivered to them. There are multiple dimensions to consider when evaluating the effectiveness of a given curriculum or approach to educating on taboo topics. Below are four questions that should be addressed while evaluating any attempt to teach a taboo topic:

How socially acceptable is the approach? Being able to coexist with cultural norms is of critical importance in educating about a taboo topic. There are many advocates of addressing taboos "head-on" by providing materials which themselves become taboo. This approach will limit whether the materials will ever be used in the contexts in which they are most needed. Later in this chapter, ways to promote social acceptability are discussed, for instance, integrating images that are acceptable to learners.

How accurate/complete is it? This is normally not a consideration for evaluating curricula in general because it is assumed that all materials within a competently designed curriculum will be accurate. However, in educating about taboo topics, there are often tradeoffs that must be made, for example, between social acceptability and accuracy. If a curriculum is accurate to the point of being blunt about a topic whose discussion is taboo, then it will fail the social acceptability test. In other cases, the curriculum may be accurate but incomplete, leaving out the most taboo details in order to provide education on related but less taboo ones. This dimension includes the level of inclusion of specific information about a topic and not simply what is covered being accurate. The best curricula will find a way to present accurate and relatively complete information using an alternate vocabulary, medium, conceptual model, or other approach, in order to keep the materials socially acceptable.

How effective is it? It is not sufficient for a curriculum to be socially acceptable and accurate/complete—it must also be effective and result in learning and retention (and where appropriate, attitude and behavior change). An educational approach may be too technical, foreign, esoteric, or otherwise ineffective, and that will override any advantages in other domains it may have.

How easy is it to deploy? The greatest theoretical educational approach in the world will not produce results unless it can actually be deployed in the real world. Infrastructure, language, and cost considerations are examples of the additional dimensions along which a curriculum must be evaluated.

The last two criteria—efficacy and ease of deployment—are the typical dimensions upon which general curricula are evaluated. Social acceptability and accuracy are unique dimensions for curricula on taboo topics.

The following table illustrates how different approaches to teaching taboo topics have advantages or disadvantages along these four dimensions.

Table 2. Advantages and Disadvantages of Framework for Evaluation

	Social Acceptability	Potential Accuracy/ Completeness	Potential Efficacy	Ease of Deployment
Avoidance	High	Low	Low	High
	No education is being provided	No education is being provided	No education is being provided	No education is being provided
Metaphors &	Medium	Medium	Medium	High
Euphemism	Depends on the nature of the taboos and the metaphors and euphemisms	Depends on the nature of the taboos and the metaphors and euphemisms	Depends on the nature of the taboos and the metaphors and euphemisms	Deploying alternate curriculum based on context
Technical	Medium	High	Medium	High
Terms	Depends whether the designer/educator can find appropriate ones to fit context	Technical terms can actually be more precise	May be hard to understand and challenging to train instructors	Deploying alternate curriculum based on context
Direct	Low	High	Medium	Medium
Approach	You cannot address the taboo subjects directly	Implies that effectively anything can be said	Being overly blunt about taboo topics can distract from what is being taught	There may be resistance from instructors and channel owners
Localization	High	High	High	High
	Materials are culturally-appropriate, enhancing acceptability within the local community	Depends on how complete the materials are presented	Depends on context and application of localization methods	Deploying alternate curriculum based on context

Based on **Table 2**, there are two important observations which should be made. The first is that it is possible (and in fact typical) for different approaches to be combined in any given curriculum. For example, for certain sections of the curriculum, metaphors may be used, while for others technical terms or a direct approach may be used. The second observation is that a localized curriculum has the potential to fulfill all of

the key requirements that have been identified, so in contexts where taboos around a topic are prevalent, localization will almost certainly be a required feature of the curriculum.

Drawing on the previous conceptualizations and evaluation criteria is a case study which provides a detailed description of the development of a new curriculum to teach about a highly taboo topic – HIV/AIDS – in India. Its goal was to maximize the various categories introduced in the framework on evaluation and ground them in pedagogical techniques and communication strategies to create materials appropriate for learners.

The remainder of this chapter will provide background for the HIV/AIDS case study, review literature and strategies to combat and educate around HIV/AIDS in India, and present arguments for a technological solution appropriate for particular taboo contexts. Next, pedagogical techniques and communication strategies needed to create materials appropriate for learners will be presented. These techniques ground a consideration of the various categories introduced in the framework by demonstrating both design and evaluation based on them.

## 3 Case Study Background: HIV/AIDS Education in India

In India, HIV/AIDS is one of the most challenging taboo topics and contexts for educators. The taboo around openly discussing topics like sexual practices, among other sensitive ones, has made addressing HIV/AIDS either taboo or extremely difficult. The fact that this single subject matter compounds several taboo topics into a single discussion (e.g., commercial sex work, homosexuality, adultery, premarital sex, intravenous drug use and death) presents unique and particularly difficult challenges. If a sound educational approach can be created to effectively address such a complex topic, similar approaches may be employed to tackle relatively less taboo topics.

The following sections provide more detailed information on the particular context in India and previous attempts to education on HIV/AIDS education. Following this will be a detailed description of how the technological solutions employed to address these challenges, while incorporating key communications and pedagogical theories and approaches to promote efficacy of the application.

## 3.1 The Challenge and Opportunity

One of the greatest public health challenges facing the world today is how to provide effective health education in Asia. With more than 60 percent of the world's people residing in Asia, the provision of effective prevention and awareness of communicable diseases in this region has direct benefits for the rest of the world, just as not doing so has direct negative consequences. As witnessed during the near pandemic of Severe Acute Respiratory Distress Syndrome (SARS) originating in China in 2002, deadly diseases can now spread within days around the world. So, prevention is far more important and achievable than containment. The primary global example of this today is HIV/AIDS, with which 33.2 million people worldwide currently live (UNAIDS, 2007). Asia has 14.4 percent of all HIV/AIDS infected people in the world, and India has the world's third-largest national infected population, after South Africa and Nigeria (UNAIDS, 2007).

Disease prevention and management is facilitated when modes of disease transmission can be discussed openly, as was the case for SARS. Historically, illnesses like leprosy, cholera and syphilis, have also been stigmatized (Herek & Glunt 1988; Pradhan, Sundar & Singh, 2006; Valdiserri, 2002). Diseases such as HIV/AIDS that are transmitted sexually, including via commercial sex workers and intravenous drug use, present significant challenges because social stigma often precludes such open discussion (Pradhan et. al., 2006; Valdiserri, 2002). Last year, various organizations spent ten billion USD on HIV/AIDS programs through private donations and government funding in developing countries alone (Sharma, 2008), in hopes of, among other things, raising awareness and curbing stigma.

Solving the problem of how to provide effective health education on diseases subject to social taboos is an immediate need. The social stigma of HIV/AIDS is particularly prominent in the developing world, which

has 95 percent of all HIV-infected persons (Noble, 2007). One study comprised of 433 students, faculty and technical staff of public health services in South India found that 42 percent of respondents believed seropositive individuals should be quarantined, 31 percent said that infected students should be kept out of classes, and 36 percent stated that it would be better for everyone if persons with AIDS killed themselves (Ambati, Ambati, Rao, 1997). This kind of stigma not only makes it difficult to provide awareness and prevention-related education, but it also complicates estimates of societal levels of high-risk behaviors and disease prevalence. In fact, nine out of ten people infected worldwide do not know they are seropositive for HIV (Singhal & Rogers, 2003). In Asia, the challenge is significantly exacerbated by the social stigma associated with discussing sexual practices or anything at all related to sex (Bennett, 2000; Reuters, 2006; Sharma, 2005; Solomon & Chakraborty, 2004; Wong, Lee & Tsang, 2004;). In many states of India<sup>5</sup>, the National AIDS Control Organization (NACO)-issued sex education curriculum<sup>6</sup>—which included the official HIV/AIDS education curriculum—has been banned entirely from public schools (Chadha, 2007; Gentleman, 2007; Sabha, 2007; Sify News, 2007; Zaheer, 2007). This is despite reports showing that pre-marital sex is increasingly common among young people (Abraham & Kumar, 1999; Bio-Medicine, 2005; Biswas, 2003; Sachdev, 1998; Sharma, 2005). One study, which Sharma (2001) notes was suppressed by India's Health Ministry, found that a quarter to a third of India's young people (ages 15-24) living in slums in Delhi and Lucknow are engaging in premarital sex (Sharma, 2001). In a 2002 survey by The Week Magazine, 69 percent of unmarried young males and 38 percent of young females admitted to premarital sex in India (The Week, 2002, as cited in Sharma, 2005; The HIV Update International, 2002).

India also presents a unique opportunity to explore and deliver innovative methods of HIV/AIDS prevention education. Many agencies have predicted India will be the next hot zone for HIV/AIDS, shifting the epidemic's center from South Africa (Padma, 2005; Perry, 2005; Sudha, Vijay & Lakshmi, 2005; Yang, 2003). With approximately 2.5 million infected individuals (UNAIDS, 2007), it is imperative to provide effective prevention education as the virus continues to spread. However, India's socially conservative culture often prevents open communication of transmission-related information. Furthermore, India's diverse population, consisting of dozens of distinct cultures, over 200 languages and dialects, and significant class-related issues, presents daunting challenges. Any form of education must consider the complex culture, history, and regional differences in order to raise awareness and promote change in knowledge, attitudes, and beliefs.

With the increasing number of HIV-positive individuals and the current ban on sex education by several state governments (Chadha, 2007; Gentleman, 2007; Sabha, 2007; Sify News, 2007; Zaheer, 2007), it is clear that an alternative method of delivering prevention education is required in order to delay the spread of the virus. According to the National AIDS Control Organization in India, the primary mode of transmission is via sexual fluids. Sexual transmission accounts for 86 percent of HIV infections in India today, followed by other means such as injection drug-use (2.4 percent), blood transfusion and through blood products (2.0 percent)—iatrogenic transmission—and vertical transmission (3.6 percent) among other unspecified routes (6.0 percent) (National AIDS Control Organization, 2005, as cited in, Correa & Gisselquist, 2006; UNAIDS, 2007).

Several recent studies indicate that Indians generally lack accurate knowledge about transmission and tend to be unaware of health-related resources, even in relatively well-educated circles (Perry, 2005; Pramanik, Chartier & Koopman, 2006). For example, a recent survey found that 59 percent believed there is a cure for HIV available (Medical News Today, 2007). Another study found that although college students were more open to premarital relationships and sexually active, they were "ignorant" of issues around sexual anatomy and functions (Sachdev, 1998). The virus is also no longer limited to high-risk populations, such as commercial sex workers and truck drivers, and has spread throughout the general urban and rural populations with presence in all states and union territories (Avert, 2009; Noble, 2007; Solomon, Kumarasmy, Ganesh &

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<sup>&</sup>lt;sup>5</sup> The states of Gujarat, Madhya Pradesh, Maharashtra, Karnataka, Rajasthan Chhattisgarh and Kerala have banned or refused the use of the official curriculum (Gentleman, 2007; Zaheer, 2007).

<sup>6</sup> The official curriculum called the Adolescence Education Programme was developed through the Ministry of Human Resource Development and NACO together (Sabha, 2007).

Amalraj, 1998; UNAIDS, 2007). In fact, most seropositive individuals fall outside of the high-risk groups (Avert, 2009), including the rich and poor, with infection rates among young people and women progressing at an alarming rate (Cichocki, 2007; Sharma, 2008; UNAIDS, 2007).

As a result of all of these factors, there is clearly a need to develop new means of providing effective prevention education for the general population in India. Although the estimated prevalence  $(0.2 - 0.5 \text{ percent})^7$  among adults (15-49) living with HIV is low relative to other countries (UNAIDS, 2008), with such a large population in India, a mere 0.1 percent increase in prevalence will result in an estimated more than half a million additional infections (Avert, 2009).

The official numbers may underestimate the true infection rate, since a large number of HIV/AIDS cases go unreported (National AIDS Control Organization (NACO), 2006; Avert, 2009). There are several reasons for this. First, individuals may not know they are seropositive since a characteristic of the disease is an ability to live for many years without any AIDS-defining clinical symptoms (Derlega & Barbee, 1998). Early symptoms are similar to the influenza and HIV is asymptomatic (Ambati et al., 1997; Porter, 1993).

Second, although there has been a vast increase in HIV sentinel surveillance sites (176 in 1998 to 1134 in 2007) (NACO, 2007), individuals may avoid getting tested or reporting their infection for fear of being stigmatized and/or ostracized by their family, healthcare officials and the community at large. Singhal and Rogers (2003) describe HIV/AIDS patients and their families as a new class of 'untouchables'. In fact, the stigma is so strong in India that unlike nearly every Western nation, no famous Indian personality has ever publicly disclosed their HIV-positive status even though several have been infected (Singhal & Rogers, 2003).

Third, according to many experts, some officials may have downplayed the crisis and/or exaggerated the positive effects of its educational efforts (Padma, 2005). In 2005, the Indian government announced that, in one year alone (2003 to 2004), it was able to reduce the rate of new infections by 95 percent (Perry, 2005); the Health Minister claimed that India reduced the 520,000 new infections in 2003 to a low 28,000 in 2004 (Mukherjee, 2005). Furthermore, some states previously said to have had hundreds of thousands of HIV-infected people were deemed AIDS-free (Perry, 2005). The figures were met with mass disbelief from various international agencies and health experts working in the field, claiming that they were misrepresentative of the underlying data and that the ground realities were different (Padma, 2005).

### 3.2 Identifying the Source of the Taboo Topic

Designing an effective solution requires first understanding the primary source of the taboo and discussing the possible reasons for its existence. Specifically, for this case study, is the dearth of sex education or HIV/AIDS education in Indian schools related to a desire to oppress the weaker members of Indian society in some way? In other words, is HIV/AIDS education withheld as a form of intentional repression or is it a desire to reinforce certain power relationships?

Systematic and intentional repression based on power relations does not appear to account for the HIV/AIDS stigma in Indian society. India is a relatively conservative society, where members of the opposite sex holding hands or kissing in public may lead to fines or worse<sup>8</sup>. These penalties are applied equally to men and women. In 2006, conservatives asked Vasundhara Raje, the Chief Minister of Rajasthan, to resign after she offered a ceremonial kiss on the cheek to welcome a businesswoman friend at the World Economic Forum (Dhillon, 2006; Sappenfied, 2007). Bollywood actors generally cannot kiss in movies, and the limits of what is considered indecent is much lower than in occidental societies. Shailendra Dwivedi, a lawyer in Madhya Pradesh, filed a criminal case against a kiss between two actors in the movie *Dhoom 2* (released

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<sup>&</sup>lt;sup>7</sup> Estimates based on 1122 sentinel sites and the National Family Health Survey, a country-wide community based household survey (NACO, 2007).

<sup>8</sup> There is a fine of \$12 for kissing in public in Delhi (Sappenfied, 2007).

November, 2006) accusing "the stars of lowering the dignity of Indian women and encouraging obscenity among India's youth" (Dhillon, 2006). Perhaps one of the most controversial public displays of affection was in April 2007 between Hollywood actor Richard Gere and Indian actress Shilpa Shetty. Gere embraced Shetty and kissed her several times on the cheek at an AIDS awareness rally in New Delhi. Following this event, protestors shouted "death to Shilpa Shetty," while demonstrators burned effigies of Gere (BBC News, 2007). News of the public kiss was carried on the front page of numerous Indian newspapers. Gere publicly apologized numerous times and according to BBC News, Shetty said, "[Richard Gere] especially told me to tell the media that he didn't want to hurt any Indian sensibilities" (BBC News, 2007). A court in Jaipur, Rajasthan issued a warrant for Gere's arrest on charges of indulging in an obscene act (BBC, 2007; Hindustan Times, 2007; Singh, 2007), however, he was cleared of the charges, and the case was thrown out by the Supreme court (BBC, 2008). As such, there is a strong taboo against public displays of affection and discussing topics around sexual practices openly, which is directly related to these cultural values.

While many taboos around ideas or topics are relaxed when presented in professional (e.g., medical, governmental, or educational) settings, the taboo against discussing sex openly, in many Indian classrooms, is just as strong. There is a widespread belief amongst Indian parents that open discussions of sex and related topics – even in the classroom – is obscene and may lead to higher incidences of pre-marital sex and other indecent behavior (Dhillon, 2006; Smith et. al., 2003).

This point of view is not unique to India. It is shared by proponents of abstinence-based sex education even in the United States. In fact, this view is so strong among certain groups in the United States that the federal government, which has not had any set initiative for comprehensive sex education, has increased funding for abstinence-only programs from \$9 million in 1997 to \$176 million in 2007 (Howell, 2007; Masters, Beadnell, Morrison, Hoppe & Gillmore, 2008), despite the government's own federally-funded evaluation of numerous abstinence-based programs indicating they do not delay sexual initiation, reduce teen pregnancy or sexually transmitted infections (Avert, 2009; Howell, 2007; Mathematica, 2009). Although some reports suggest positive effects of abstinence-only or "abstinence until marriage" initiatives, experts claim these studies are not methodologically sound or do not provide robust empirical evidence indicating a strong case (Oakley, Fullerton, Holland, Arnold, France-Dawson, Kelley & McGrellis, 1995). The Society for Adolescent Medicine has stated that, although abstinence should be included as one of the many options within comprehensive sex education programs, funding towards abstinence-only programs should be replaced with funding for medically-accurate comprehensive sex education (Masters, 2008; Society for Adolescent Medicine, 2006).

Empirical research has shown that comprehensive sex education is actually more effective than abstinence-only programs in delaying sexual initiation and other perceived negative sexual outcomes (Kirby, 2002; Masters, 2008; Santelli, Ott, Lyon, Rogers, Summers & Schleifer, 2006; Sharma, 2005). Moreover, sex and HIV/AIDS education programs do not increase sexual behavior either in the United States (Kirby, 2002) or in the developing world (Kirby, Obasi & Laris, 2006; Kirby, Laris, Rolleri, 2007). However, this is generally not believed by conservatives throughout the United States and certainly not by many parents in India.

As a result of this skepticism, numerous state governments across India (e.g., Maharashtra, Gujarat, Madhya Pradesh, and Karnataka among others) have banned sex education in public schools altogether. However, it is important to note that this is limited exclusively to school curricula and does not mean these topics are censored for adults. Thus, banning sex education among students does not fit the typical pattern of oppressing groups in order to dehumanize them in some way, because of course, children will eventually become adults and be immune to such control. Instead, it is more typical of the social and legal limits that all societies set for young people in the belief that it will protect them from harm and allow them to grow in the desired way.

An alternate explanation for the state of HIV/AIDS education in Indian society is that the government is not interested in actually providing these resources since the disease disproportionately affects lower social classes. Similar to criticisms and conspiracy theories relating to the U.S. government, this hypothesis seems to

have no basis in fact. The National AIDS Control Organization (NACO) operates under the division of the Ministry of Health & Family Welfare to manage the AIDS epidemic in India. NACO has established 35 HIV/AIDS control societies across all Indian states and Union Territories to respond more appropriately to spread of the virus and coordinate a national response (Avert, 2009; NACO, 2008). NACO has been given an extremely large budget by Indian standards. Launched in 1992, Phase I of the National AIDS Control Program received \$99.6 million USD to, among other things, establish and strengthen management capacity in the country, promote public awareness, improve blood safety (Claeson & Alexander, 2008). Phase II included a budget of \$460 million included activities around providing prevention interventions for at-risk groups and the general population as well as AIDS care initiatives (Claeson & Alexander, 2008; NACO, 2009). 9 For Phase III, which takes place between 2007-201110, the Indian government budgeted a 2.5 billion USD dollar response<sup>11</sup> to the epidemic, with 70 percent earmarked towards prevention efforts (Araujo, 2008; Avert, 2009). This phase includes targeting high-risk groups with evidence-based prevention methods (e.g., condom promotion, peer education), among other activities (Claeson & Alexander, 2008). In addition, there are more than 1000\* NGOs, many of which are funded by NACO, working on HIV/AIDS prevention and treatment issues across the country. NACO has also partnered with other organizations to launch campaigns like the Red Ribbon Express, which is a seven-coach train filled with health materials travelling to 166 districts across 23 states in the country (Avert, 2009; NACO, 2007). Public billboards and public service announcements are not difficult to find.

Overall, the taboos surrounding HIV/AIDS relate directly to either the taboos around discussing sexual topics or taboos relating to actions or states which are either illegal, highly controversial, or both.

It should be noted that there is a significant difference between merely mentioning, or using the phrase, HIV/AIDS, and actually discussing it. As long as none of the taboo elements relating to it are mentioned, a simple message along the lines of "think about AIDS" is acceptable in many circumstances in which full discussion would not be acceptable. The conflicts with taboos inevitably arise when one attempts to engage in a more comprehensive discussion about the topic, especially about prevention.

A distinction should also be made between taboos concerning actions or states and communications taboos relating to HIV/AIDS. For example, drug-use is taboo, but there is no communications taboo associated with it, as there is universal agreement on what the message should be—"say no to drugs". On the other hand, homosexuality is considered a taboo state by many in India, but it also has communications taboos associated with it. This is because it falls into the category of actions or states relating to HIV/AIDS that are not discussed in schools due to their political divisive nature. That is, there is no clear popular consensus on what the overall message relating to that topic should be. While everyone can agree on drug-use being harmful, homosexuality on the other hand is an issue which takes on a political nature in India—as it does in many countries—and, as a result, there are those who would oppose a message of acceptance as well as those who would oppose a message of condemnation. Considering that homosexual acts were de jure illegal until July of 2009 in India, this is not surprising. Even in the United States, most public schools do not teach about homosexuality because of this similar political divide (Jan, 2006; Newsom, 2008).

Discussions of HIV/AIDS can likely be had without choosing sides, either advocating or denouncing the associated activities or states which are considered controversial. Of course, there are some people and groups who perpetuate the mistaken belief that HIV/AIDS only affects minorities, or even that HIV/AIDS is a form of divine punishment for what they consider to be immoral acts (Kopelman, 2002; Redjimi & Lert,

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<sup>&</sup>lt;sup>9</sup> This includes funding from the Government of India, World Bank, USAID, CIDA, United Nations Development Program (UNDP), AusAID, Global Fund and DFID.

<sup>10</sup> Minister for Health & Family Welfare, Dr. Anbumani Ramadoss launched the Third Phase of the National AIDS Control Program in July of 2007 (NACO, 2007)

<sup>11</sup> Phase III funding is from a combination of resources including, the Government of India, non-governmental organizations, international non-governmental organizations, industry and other agencies (e.g., World Bank, Bill and Melinda Gates Foundation) (Avert, 2009).

1993). For them, the provision of HIV/AIDS education to the general population is not only unnecessary but would constitute tacit approbation of those activities or states, and thus they would oppose HIV/AIDS education itself. Fortunately, that mistaken viewpoint is in the extreme minority, and most people recognize the public and personal benefit of teaching others to protect themselves against an incurable, transmissible, and fatal disease.

Thus, the question which remains is how to provide complete, accurate, and effective HIV/AIDS prevention education without using methods, messages, or language which automatically trigger societal rejection due to conflict with the aforementioned taboos. It is precisely these challenges and opportunities that lead researchers to ponder whether a curriculum could be devised to improve knowledge and change attitudes, despite these barriers (Sorcar, 2009).

#### 3.3 Previous Attempts at HIV/AIDS Education

In many cases, laws and social norms prohibit the delivery of sexual health information through the standard educational, medical, or public health systems. Numerous studies have documented stigma and discrimination faced by patients from medical professionals (Kurien, 2007; Leary & Schreindorfer, 1998). In fact, although the National AIDS Control Organization (NACO) in India advocates confidentiality, one study presented at the 2002 International Conference on AIDS revealed that 95 percent of patients registered for surgical procedures were not only involuntarily tested for HIV, but their surgeries were cancelled if they tested seropositive (Malavade, Shah, Shah, Shah, 2002; United Nations Population Fund, 2009). Hence, there has been heavy emphasis in India in launching HIV/AIDS awareness campaigns through the mass media (e.g., messages on billboards, posters, television spots, radio ads) in order to reach large populations. There have been large-scale combined efforts by news organizations, foundations, and the Indian government to spread awareness through the mainstream media (James, Hoff, Davis & Graham, 2005). Although this method is capable of simultaneously reaching a large number of people to raise awareness, there are many reasons why its exclusive or primary use is incapable of stemming the HIV/AIDS epidemic.

Educational campaigns via mass media have been constrained by cost. Because advertising is priced according to time and space used, educational advertisements are dispersed in terse segments (e.g., television spots are approximately thirty seconds to two-minutes, billboards usually carry one or two messages). Examples of these include the Buladi campaign launched by the West Bengal AIDS Control Society, and the Balbir Pasha campaign launched by the Population Services International. It may be difficult for learners to build knowledge based on these brief presentations, as these campaigns involve limited durations of exposure.

Second, depending on the type of media, there are intrinsic limitations on the impact on key sub-populations. For example, television ads are only accessible to homes with television sets. Going one step further, television sets are only available to homes with electricity. Thus, individuals who see television ads at home, tend to have a significantly higher socioeconomic standing. However, the groups most lacking in basic HIV/AIDS education are often of lower socioeconomic standing. HIV/AIDS messages on billboards are usually expressed in written text, which limits their impact to the 62.5 percent of the population that is literate (Census of India, 2001). Even more problematic, women who are in remote villages are less likely to be exposed to any kind of HIV/AIDS media campaigns at all. A 2006 survey, conducted by the National Family Health Survey (NHFS), found that 70 percent of women in rural Bihar had not even heard of HIV/AIDS (Mishra, 2007).

Finally, mass media campaigns only allow for one-way communication—learners receive the messages but are not able to ask questions or immediately follow-up in any way. It is, therefore, difficult to gauge whether the correct messages are being acquired and spread through these channels. It is also difficult to isolate the effects of particular messages, making it impossible to identify and study targeted improvements from one campaign to the next.

Because there is no cure for HIV, and antiretroviral medications are out of reach for most of India's population (in that they are too expensive and must be taken for an infected person's entire life), prevention is critical in curbing the spread of the epidemic. Although numerous educational materials and interventions are available throughout the world, many are developed by medical personnel, who while having the best intentions and being well-versed in diagnosis and treatment, are less familiar with developing pedagogically-grounded and effective curricula (Singhal & Rogers, 2003). When educating about communicable diseases, being able to adapt curricula to pre-existing notions of behavior is imperative for content to be assimilated in a coherent fashion. The ability to understand and apply HIV prevention strategies properly, especially in high-risk situations, is vital to preventing transmission. At a minimum, properly understanding prevention strategies could significantly curb stigma and fear-related issues associated with the subject. Hence, the development of highly effective education messages should be based on formative assessments, pedagogically sound messages, and culturally appropriate materials. The framework for evaluation can be used to determine whether curricula relating to taboo topics, is likely to be effective for the target group.

#### 3.4 Cultural Challenges

Many activists argue that the socially conservative nature of many Asian cultures put vulnerable populations at extreme risk. In their view, it is the responsibility of the government to help change those cultures to make them more progressive and capable of openly discussing sexual practices (Medical News Today, 2007; Mukherjee, 2007; Sundaram, 2007). Changing ingrained cultural norms, however, is difficult and is obviously opposed by many conservative groups. In addition, democratically elected governments are generally not eager to tell their constituents that their cultural values are in any way incorrect or outdated. [In India, for example, homosexuality is considered a taboo topic by many and a was de jure criminalized until June 2009:

Whoever voluntarily has carnal intercourse against the order of nature with any man, woman, animal shall be punished with imprisonment for life, or with imprisonment of either description for a term which may extend to 10 years, and shall be liable to fine. (Section 377, Indian Penal Code, 1860)

This provision deterred certain marginalized populations from getting tested for HIV out of fear of being ostracized or even imprisoned for their behavior (Agoramoorthy & Minna, 2007). There is also the issue of paternalism: it is difficult to justify an intervention that labels a culture as flawed.

Mass media campaigns aimed at promoting educational messages that do not properly stress evidence-based prevention strategies may actually have devastating effects on society. Decision-makers of each state may continue to ban sex and HIV/AIDS education in schools, claiming that the media campaigns, albeit ineffective, are providing enough education. As such, these mass media campaigns are mere band-aid solutions that do not address many of the root causes of the problem. Moreover, these campaigns do not adequately address many of the underlying issues, such as gender-based inequalities, which promote the spread of the virus through the population.

## 3.5 Why Technology and Not Teachers

Although open discussions between students and educators would be an ideal method of imparting accurate knowledge and correcting myths and misinformation, many teachers across India do not feel comfortable addressing the topics of sex or HIV/AIDS in the classroom. Since HIV/AIDS is directly related to other sensitive subjects its relationship to these taboos makes it even more challenging to discuss openly. Numerous studies dealing with prevention education have found teachers reticent and uncomfortable to discuss sexual matters with their students (Kirby et al., 2006; Nayak & Bose, 1997; Smith et al., 2003; Verma, Sureender & Guruswamy, 1997). In 2007, teachers in Uttar Pradesh publicly burned materials in bonfires to protest sex education (India Together, 2008).

Waiting for a country's culture and laws to change, or even trying to change it, is not a viable means of warding off a possibly immediate pandemic. New approaches must be created to provide education despite

whatever social, structural, cultural, and legal barriers exist. Fortunately, the emergence of new media and ICT has provided possibilities for innovative ways to help bypass social taboos and provide effective messages in ways that were simply not possible in the past. Self-guided learning mechanisms, whether book, audiotape, or a computer application, allow learners to assimilate information in a private learning spaces, free from public scrutiny and embarrassment. This freedom from embarrassment also applies to teachers, who often choose neither to teach about taboo subjects nor emphasize curricula with which they themselves are not comfortable. Additionally, ICT is superior to books and tapes from a monitoring perspective because ICT is inherently trackable—one can know exactly how many learners completed the application, how long it took them to answer particular questions, as well as whether they were able to answer questions correctly. Powerful insights can be gained from granularly tracking how learners interacted with individual modules, enabling one to rapidly improve the efficacy of the applications. Furthermore, Internet applications are amenable to a multitude of functions, for example, providing and exchanging information, use of simulationbased modules, facilitating decision-making and action planning, promoting specific behaviors and self-care, providing social support, and managing demand for health services (Nguyen, Carrieri-Kohlman, Rankin, Slaughter & Stulbarg, 2004; Nguyen, Cuenco, Wolpin, Benditt & Carrieri-Kohlman, 2007; Orlandi, Dozier & Marta, 1990; Sampson & Krumboltz, 1991), which are essential to improving health outcomes. Finally, ICT allows designers to both standardize best practices and readily adapt content to local needs (e.g., adaptation for language, ethnicity, gender differences as well as differing levels of familiarity with the subject).

In some cases, providing education via ICT can actually be more effective than other more traditional means, and hence have been advocated in public health circles (Burnett, Magel, Harrington & Taylor, 1989; Lightfoot, Comulada & Stover, 2007; Orlandi et al., 1990). A recent computer-based HIV prevention intervention, targeted towards delinquent youths in the United States, found that youth exposed to the computer-based intervention were significantly less likely to engage in sexual activity, relative to the non-computer-based group and control group (Lightfoot et al., 2007). Also, the computer-based group reported fewer partners in the follow-up three months later (Lightfoot et al., 2007).

As new forms of ICT have been created, so too have learning applications utilizing those technologies. Some of these applications are for big-screen (projection) formats, while others are for smaller formats such as mobile devices. These types of applications can be used to communicate a message to large groups or one person at a time. Each approach has advantages and disadvantages. Furthermore, some educators choose to use ICT as a form of "edutainment" to enhance comfort or in cases when the teachers may not be as familiar with a subject. The use of technology-based learning has enabled new forms and formats for learning beyond the traditional model of in-person, linear, real-time instruction.

Given the structural, political, legal and cultural constraints in providing effective and yet accessible prevention materials, an interdisciplinary team of experts was assembled to explore these daunting challenges and work towards building an educational approach which could be accessed more openly by the Indian society.

## 4 Constructing a Technological Solution

#### 4.1 Foundation for Educational Software

While working with an interdisciplinary team of experts at Stanford (spanning the fields of public health, communications, human computer interaction and education), Piya Sorcar designed and authored an interactive HIV/AIDS prevention application to specifically avoid the taboos and other cultural barriers that have impeded AIDS education and resulting changes in behavior. The software provides detailed, yet accessible and acceptable, discussions of all aspects of HIV/AIDS and hence had the potential for widely altering the knowledge and associated risk behaviors of Asian youth and adults (Sorcar, 2009).

With various bans on sex education, access to AIDS education is limited in many Indian communities (BBC News, 2007; Mukherjee, 2007). Since HIV/AIDS is a taboo subject in India, a major design consideration for this tutorial was to maximize comfort levels among learners while they were interacting with the software.

After learning that despite hundreds of millions of dollars spent on HIV/AIDS prevention in India, basic knowledge of transmission was still limited, further investigation was needed. Several first-generation Indian undergraduate and graduate students who had recently migrated to the United States from India were interviewed about these issues. Because of the deeply sensitive nature of topics relating to sexual practices, researchers had to build trust with students before asking them questions relating to their personal experiences.

Based on IRB-approved research conducted on several hundred young adults in India, a team of interdisciplinary experts and researchers at Stanford University were recruited to develop an application to bypass Asian cultural sensitivities and yet provide highly effective prevention education (Sorcar, 2009). *Interactive Teaching AIDS* was an ICT-based application aimed to provided research-based, culturally-appropriate HIV/AIDS prevention education to audiences where discussing topics related to sexual practices is often considered taboo. The pilot application, which took two years to develop, test, and optimize, was initially designed only for an Indian audience and targeted young adults, but has since been adapted for learners throughout the world.<sup>12</sup>

The application used a question-driven approach. The questions in the animated tutorial were based on: 1) the most frequently asked questions by learners in the design phase and 2) the most misunderstood facts about HIV/AIDS transmission and prevention. Furthermore, unlike other curricula which is either purely scientific (e.g., HIV transmission discussed in the context of virology or infectious disease) or teaches learners to avoid the questionable activity entirely (e.g., "Just Say No" and other abstinence-based sex education campaigns), this method utilized an entirely different approach. To maximize comfort and promote coherent understanding, it coupled biological aspects of transmission with culturally familiar euphemisms and metaphors to communicate ideas around prevention measures, utilizing numerous education and communication theories. Entertainment education has been documented as being a powerful tool to bring sensitive subjects, such as HIV/AIDS, into public discourse (Piotrow, Kincaid, Rimon & Rinehart, 1997; Singhal & Rogers, 1999).

The ITA tutorial was based on numerous pedagogies and theories explored in the following section. It focused solely on knowledge gain and bypassed taboos by carefully avoiding challenging cultural norms or making normative statements. The tutorial was also designed to be highly flexible because it used animations rather than live actors. There were separate male and female versions of the application, incorporating both male and female doctor and student characters for various target groups.

## 4.2 Developing a Coherent Conception: The Fan Effect

Media campaigns about HIV/AIDS that are limited in scope (e.g., billboards carrying one or two main messages, or television ads of 30 seconds to 1 minute) can cause misconceptions if the learner does not have a firm grasp of the basic concepts. Learning about HIV/AIDS protective measures is in some ways analogous to learning to drive. If a student learns about using the car mirrors from a billboard, turning the wheel from a television commercial, and utilizing the car breaks from a radio ad, it would be challenging for them to piece all the concepts together to drive a car properly. Imagine this difficulty coupled with the inability to ask those around you open questions about driving because it was a sensitive or taboo subject. Similarly, learners receive fragmented data about HIV/AIDS transmission through various mass media campaigns in India, making it difficult for them to create a coherent overall picture for prevention and understanding.

<sup>12</sup> The Interactive Teaching AIDS applications can be accessed at www.TeachAIDS.org.

Furthermore, the misunderstandings may become even more convoluted when they are coupled with the reticent behavior of individuals of all ages around this subject.

Research shows that expert knowledge centers on concepts that are connected and assembled in an organized fashion (Bransford, Brown & Cocking, 1999). Usable knowledge is, therefore, quite different from a large set of disconnected facts.

Fan Effect learning theory shows that the more individual facts that a person learns about a single concept, the more difficult it is for them to retrieve particular facts from memory (Anderson, 1974; Anderson & Reder, 1999). This retrieval mechanism is especially difficult when the set of facts do not have an internal cohesiveness or integration (Spoehr, 1994). Furthermore, connecting facts in a coherent fashion allows learners to build patterns and relationships leading to a deep understanding as well as greater transfer to novel situations (Bransford et al., 1999).

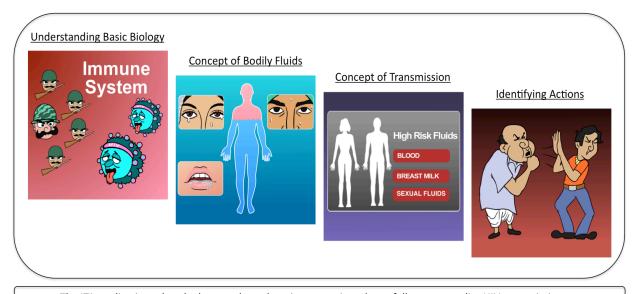
One common way educators present health education in a cohesive manner is through a list of "DOs" and "DON'Ts" (e.g., do take steps to protect yourself, don't engage in risky behaviors). Previous research on effective methods to promote HIV prevention has shown that this presents "superficial knowledge" and is therefore unlikely to translate into actionable prevention methods and may even increase fear among learners (Au & Romo, 1996; Au, Roma & DeWitt, 1999). When teaching about HIV/AIDS prevention to young people, it is imperative to avoid fragmented knowledge (e.g., "dos"and "don'ts") and focus on creating a coherent conception (e.g., teaching concepts around bodily fluids, fluid transmission). This allows students to organize considerable information, as well as to learn to reason through novel settings (Dooling & Lachman, 1971).

Since sex and reproductive health education is not mandatory in India, it is unclear how individuals piece together the disparate bits of information they might receive. For instance, promoting the popular ABC campaign (Abstinence, Be Faithful, Use Condoms) among people who do not understand the basics of fluid transmission can make understanding the underlying message more difficult. However, a person with limited knowledge, who follows this campaign blindly, may be especially at risk. For instance, the 'B' in 'Be Faithful' is in reference to having a monogamous faithful relationship with their partner. Consider a case where a man is having relationship with a female commercial sex worker and he is "being faithful", in the sense that he is visiting the same commercial sex worker (CSW) and, therefore, abstains from using a condom. Although he is following the advice of the ABC campaign literally, he is still at risk if the CSW is having sexual relations with other clients. 13 Similarly, a faithful wife may follow the ABC campaign verbatim; however, if her husband is having an extramarital affair, she is still at risk. Being able to simply repeat rules and campaign messages is not good enough. Individuals must understand the underlying concepts underlying these messages are grounded in. In both the above scenarios, all individuals involved are at risk of an HIV infection. With little knowledge of transmission, blindly following the advice of a public campaign can have ill effects. Due to these sorts of misunderstandings, organizations such as Population Services International have launched campaigns to improve comprehension of exactly this sort of transmission-related issue (Population Services International, 2003).

The baseline surveys coupled with the one-on-one interviews with first-generation Indians revealed several misunderstandings among the target group, such as the belief that HIV can be transmitted through kissing, hugging, or water. Several students knew that HIV could be transmitted through blood and noted they had seen ads about such educational messages. However, when asked "how" one could get HIV from blood (e.g., touching blood, licking blood), it was evident the learners had superficial knowledge about the topic. The ITA curriculum therefore, did not rely heavily on prior knowledge in order to understand fundamental concepts of transmission. Rather it introduced a broad description of how bacteria and viruses work within the body, through an analogy of soldiers within a country. It then progressed to the concept of body fluids – reviewing

<sup>&</sup>lt;sup>13</sup> Note, that an average commercial sex worker in Mumbai services approximately seven clients each night (Singhal & Rogers, 2003).

high-risk and no-risk fluids in the body. Next, the application facilitated learners to understand that high-risk fluids must literally enter the human body to create a risk of infection. Finally, the application helpd learners identify and connect various actions (e.g. coughing, hugging) with bodily fluids and transmission modes. This entire sequence was developed, through an iterative design approach based on testing, to give learners a coherent conception of how the virus survives in the human body and to provide the learner with a way of assessing whether he or she is at risk. Furthermore, providing visual representations of the concepts help to orient learners and have shown to facilitate retention (Pinsky & Wipf, 2001).



The ITA application takes the learner through various steps in order to fully conceptualize HIV transmission.

## 4.3 Balancing Social Acceptability with Accuracy and Efficacy

Although research indicates that fear-based approaches, in specific cases, can increase information processing and associated gains in learning (Kim, Sorcar, Um, Chung, Lee, 2008; Lee & Ferguson, 2002), teaching about taboo topics requires particular sensitivity to maintaining comfort for both students and administrators. Fear-based interventions tend to be highly graphic and disturbing. With the ban on sex education in India and sensitivity around subjects like HIV/AIDS, they would likely not be acceptable to traditional institutions, regardless of their efficacy.

Selecting images that are both comfortable and efficacious is both important and extremely challenging. On the one hand, communicating sensitive messages via simple representations, like stick figures, would maintain higher levels of overall comfort. However, the abstract nature of the representation might hinder accurate message communication, and thus learning. On the other hand, designers can use highly graphic and explicit images, which would communicate exact actions to best understand transmission. However, these sorts of images would be uncomfortable for learners. Feeling comfortable with the materials may further ensure that learners share information with others. The goal was to identify images that would be both clear and effective but also maximize comfort and social acceptability.

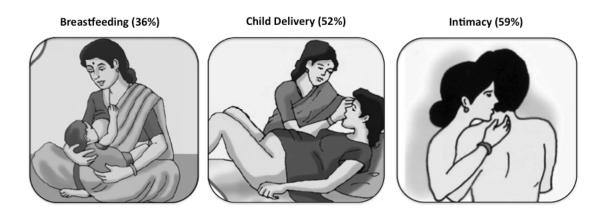
## 4.4 Identifying Socially Acceptable Graphics

A Stanford IRB-approved anonymous survey was conducted on 200 undergraduate students in New Delhi, India to better understand the mindset of young adults, assess their baseline knowledge, and understand what

types of pictures could be utilized to communicate messages and maximize comfort and learning. School officials restricted the kinds of pictures that could be tested on the students, limiting the range of the data. However, this negotiation process was highly informative, as it allowed the researchers to further grapple with the kinds of images and information allowed within the scholastic environment. The survey was rejected several times before schools finally agreed to run it on their students. With each survey iteration, questionable and uncomfortable materials were removed and resubmitted the survey for approval.

It is likely that most HIV/AIDS curricula will need to contain facts about breastfeeding, child delivery and sexual intercourse, since these are all common modes of transmission. The pictures in the survey were all simple black and white drawings from existing HIV/AIDS curricula used by local NGOs¹⁴. Below is a subset of pictures from the survey depicting these methods of transmission. The numbers associated with each picture (36 percent breastfeeding, 52 percent child delivery, 59 percent intimacy) represent the percentage of students that indicated that they were unsure, uncomfortable or very uncomfortable with the associated graphics. After reviewing these results, it was necessary to identify other images to communicate the correct messages and maximize comfort levels.

Figure 2. Selected Results from Baseline Survey



The numbers associated with each picture (36% breastfeeding, 52% child delivery, 59% intimacy) represent the percentage of young adults that responded to the baseline survey who were either unsure, uncomfortable or very uncomfortable with the associated graphics.

Researchers worked with the target group and identified culturally-sensitive pictorial depictions which communicated the concept of bodily fluids and transmission. They also explored varying degrees of humor with images, which when used appropriately, can be an effective mechanism to overcome a taboo topic (Fennell, 1993; Singhal & Rogers, 2003).

Below are a few examples of the types of pictures<sup>15</sup> the focus groups felt most comfortable with while communicating issues of transmission. These are a few examples used to devise a socially acceptable

14 Image Sources: Global Strategies for HIV Prevention, Rural Education and Development, Sahaya International, International Training and Education Center on HIV, Global Strategies for HIV Prevention and Lives in Focus.

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<sup>&</sup>lt;sup>15</sup> The Indian illustrations in the Interactive Teaching AIDS software were developed by Manick Sorcar Productions and were animated by a medical animation team through the Medical Research Information Center and Care and Visual Ltd.

approach, which was discussed as part of the framework for evaluation. The pictures on the left were tested and replaced with the pictures on the right in the ITA applications.

Figure 3. Representation of Breastfeeding



To maximize comfort, the picture (on left) representing breastfeeding was replaced by the picture (on right) exposing less skin.

For the representation of breastfeeding, learners indicated that simply exposing less of the woman's breast increased overall comfort with the image and communicated the same message. The final pictures were also less detailed in that less volumetric shading was used to flatten the image further. The picture on the right was used in the final animation.

Figure 4. Representation of Child Delivery



The picture (on left) representing child delivery was replaced by the image (on right). Through animation, the pregnant woman morphs into one holding a baby.

The final application included a simple animated sequence to convey delivery. Instead of showing a half exposed body, as in the picture (left), it featured a woman fully clothed (wearing an *Indian sari*) and then, through animation, a baby appears in her arms. The learners understood this woman to be euphemistically delivering a baby and found this imagery comfortable and even entertaining. With regards to providing information on vertical transmission, it was not the explicit knowledge of how infants are delivered that was central to creating a conceptual understanding, rather connecting the concepts related to transmission of the virus.

In order to represent intimacy, the animation incorporated ideas from old Bollywood movies from the 1960s and 1970s, which are viewed comfortably by masses in India.

Figure 5. Representation of Intimacy #1



The picture (on left) representing intimacy was replaced by a euphemistic image (on right) showing a close-up of the lovebirds kissing instead.

In the picture above, instead of showing a couple publicly kissing (which is taboo in India), the animation showed a couple coming very close to kissing and then the camera panned up a tree (away from the couple) and the lovebirds kiss instead (picture on top right). This is an example of a culturally-appropriate use of a euphemism. The target group clearly understood the concept, especially since this sequence parallels love scenes from old Bollywood movies.

Figure 6. Representation of Intimacy #2



The picture (on left) representing intimacy was replaced by a culturally-appropriate image (on right) of a bride, sitting on her honeymoon bed, decorated by ceremonial flowers, representing a sexual connection.

While discussing sexual intercourse (picture on top right), the animation included cultural elements from Bollywood movies and Indian traditions.

In order to maximize comfort, instead of showing a man and woman intimate with one another, the animation displayed an image of a woman in her wedding gown sitting on a bed decorated with flowers. This sort of floral arrangement (the tradition is called "suhag raat") takes place on the bed where a husband and wife will honeymoon on their wedding night.

#### 4.5 Application of The Media Equation

The curriculum draws on the following principle based on 35 studies described in *The Media Equation* (Reeves & Nass, 1996): people apply the same social rules and heuristics when interacting with media as they do when interacting with actual people and places. Furthermore, these responses were true of all the segments they were tested on including children, college sophomores, business people, and technology experts. These social responses to media are unconscious and automatic.

Due to the sensitive nature of this subject and discomfort among young adults to discuss it openly, ICT was chosen to deliver the ITA curriculum. *The Media Equation* suggests that students should be able to learn from the animated characters in a similar way to learning from humans, with the added benefit of knowing they are only interacting with technology. This should help diminish embarrassment or discomfort as the interaction is with a completely non-threatening technological device as opposed to a human. However, one important difference (and benefit) that was discovered through the focus groups was that learners felt less embarrassed about sensitive topics when interacting with technology instead of with other people.

While designing the animated characters and discussing their features, it was discovered that students in the focus groups felt even more comfortable if the characters did not have names associated with them. Originally, primary characters in the animation were given generic names (e.g. Raja, Rani). However, being that these names were generic, the users inevitably knew someone with those names and said they thought about them during their interaction with the curriculum. Suddenly, the students' experience did not feel "private" anymore, consistent with the ideas from *The Media Equation*. Removing character names from the curriculum had the added benefit of avoiding religious or caste classifications. Other HIV/AIDS initiatives have encountered problems with selecting names for campaign characters specifically due to the religious associations (Shah, 2006).

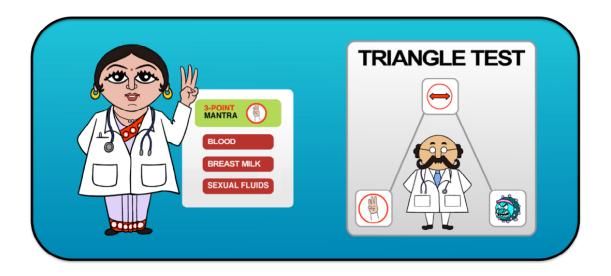
## 4.6 Mnemonic Devices as Learning Tools

Mnemonic devices, which use visual image links, have been shown to enhance retention of difficult concepts (Lorayne & Lucas, 1974; Luria, 1968). They are essentially memory aids designed to help the learner create associations between various constructs.

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<sup>&</sup>lt;sup>16</sup> Most Indian names tend to be associated with a particular religion or caste of the individual.

Figure 7. Mnemonic Device to Facilitate Learning about Fluid Transfer



The ITA application uses mnemonic devices to help learners better understand the most important concepts. Above is are examples of the 3-point mantra and the Triangle Test.

The ITA application reinforces primary concepts through various pictorial mnemonic devices. These devices were used to help students retain novel concepts. For instance, students learn about the *Three Point Mantra* (left), which outlines the high-risk transmission fluids (top left). Every time the doctor says *Three Point Mantra*, he/she (depending on the version) holds up his/her three fingers, which are used as a symbol or icon throughout the animation.

#### **3-Point Mantra** (High-Risk Fluids)

- 1) Blood
- 2) Breast Milk
- 3) Sexual Fluids

Another example of a mnemonic device is the concept of the *Triangle Test*, which helps the learner assess whether he or she is at risk in a particular situation. There are three parts to the *Triangle Test*, arranged on the three corners of a triangle. The memory aid reinforces that there are three steps for considering the risk of an infection. The doctor character uses his or her pointer to show the learner the direction to properly use this learning tool. See below for the mnemonic strategy.

Figure 8. Mnemonic Devices for Learning about Risky Behaviors



Above is the example of the Triangle Test. This use of a mnemonic device helps the learner assess whether he or she is at risk of an HIV infection.

#### Triangle Test

Step One: Is there a HIGH RISK FLUID?

If no, stop here. There is no HIV risk.

If yes, proceed to STEP 2.

Step Two: Is there DIRECT TRANSFER?

If no, stop here. There is no HIV risk.

If yes, proceed to STEP 3.

Step Three: There is a POSSIBLE HIV INFECTION.

Go see a doctor.

## 4.7 Voice Properties and Gender Concurrence

Nass and Brave demonstrate the applicability of social psychological principles of similarity attraction to the design of computer agents (Nass & Brave, 2005). They discuss the concept of homophily—similars attract—which essentially means that people are attracted to other people who are most similar to them. Participants rated agents similar to themselves as the most credible, trustworthy and friendly. Based on these findings, male and female characters with voices similar to the target audience were chosen. Because this animation was aimed towards young adults in India, voice actors with similar accents and pronunciations within the appropriate age groups were recruited.

The current animations features voices selected directly by young people in the target audience. The development team first selected five to six candidate voice actors and then uploads sample clips using an online survey tool. The students in the target group then vote on the voice choices, advocating which ones they like best, given the context. The winning voice actors then record the entire script for the animation. This is an interesting way to incorporate a participatory design approach in order to secure a better local fit for such educational tools.

The animation itself consists of a discussion between a student and his/her physician through which basic HIV/AIDS-related questions and concepts are explored in order to better understand transmission and

prevention methods. Separate versions for males and females (the male version has a male doctor and male student while the female version has a female doctor and female student) were also developed. This decision was based on the evidence that gender concordance is important while discussing sensitive issues (e.g. sex education), particularly among female patients (Fang, McCarthy & Singer, 2004).

#### 4.8 Cultural Embeddings

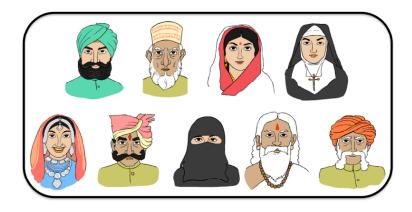
"If culture is a factor in transmission and impact, it follows that prevention and care require a cultural approach"

- Healthlink Worldwide, 2007

Experts say that cultural embeddings are an integral component to designing HIV/AIDS materials (Commission for Africa, 2005). Integrating values, beliefs and traditions into educational materials helps to build trust and engagement at the community level (Healthlink Worldwide, 2007) and has lead to greater overall program acceptance and sustainability (UNFPA, 2004). It is particularly important to use culturally sensitive materials while designing messages for highly stigmatized subjects as not to offend the learners (Singhal & Rogers, 2003). Some individuals may be interacting with the materials in order to protect themselves and their loved ones. Others may either be seropositive or know someone (e.g. family member, friend, co-worker) who is infected with the virus. Culturally-appropriate approaches have shown greater impact on promoting awareness, changes in attitudes (stigma reductions) and further inclusion of those living with HIV and AIDS (Healthlink Worldwide, 2007). It is particularly important to develop appropriate materials as life threatening illnesses, such as HIV and AIDS, can present tremendous physical and psychological distress on those infected as well as others within their social network (Derlega & Barbee, 1998).

There are several cultural elements embedded into the ITA application in order to make it familiar and appropriate for the learners. Throughout the development process, numerous individuals with expertise in India related social and cultural issues were consulted. A professional award-wining artist<sup>17</sup>, with decades of experience, was engaged to illustrate all the Indian animated characters.

Figure 9. Cultural Embeddings



The ITA application incorporates many cultural embeddings. Above are pictures of some of the characters in the animation.

17 Culturally-appropriate illustrations were developed by Manick Sorcar Productions (www.manicksorcar.com)

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The ITA application also utilizes ideas from experts who have studied India-related social and cultural issues. Several brainstorming sessions in and around Stanford were conducted, targeting Indians who had recently migrated from India, to learn about cultural sensitivities and necessities in designing further outreach of the application. In order to be consistent with the expectations of young learners, the materials incorporated ideas from popular Bollywood films, including trends, costumes choices, cultural icons, and analogies through the animated characters.

Figure 10. MS&E 17SI Course at Stanford University





MS&E 17SI: Stanford undergraduate and graduate students brainstorming ideas for the India Interactive Teaching AIDS application through a Management Science and Engineering course.

Based on feedback from the focus groups, several words, phrases and metaphors were tested and altered to be more culturally-appropriate and appear more colloquially. Interaction with experts and the focus groups revealed the importance of using particular phrases correctly to further ensure acceptance of the program. Below are some examples:

- a) The proverb "an ounce of prevention is worth a pound of cure" is more commonly said and written in India simply as "prevention is better than cure". Since the baseline survey revealed that young people had many questions around a cure for HIV/AIDS, the title for the animation became "Prevention is Better than NO CURE".
- b) Instead of saying "appearances can be deceiving", the application uses a more popular Indian derivation, "appearances are deceptive".
- c) The chapter describing viruses included a list of the most typical viruses affecting Indians (e.g., polio, chicken pox, and measles)

The learning and communication theories summarized in this chapter were carefully examined and tested piecemeal in the focus groups before combining them into the ITA application. In particular, they were used to maximize cultural appropriateness and promote acceptance of the prevention education.

## 5 Discussion & Analysis

## 5.1 Comparison of Case Study to Framework for Evaluation

**Table 3** summarizes the ITA application using the framework for evaluation described earlier in the chapter. It demonstrates how the application ideally fits into the various categories for the framework.

Table 3. Comparison of Case Study to Framework for Evaluation

	Social Acceptability	Potential Accuracy/ Completeness	Potential Efficacy	Ease of Deployment
Interactive Teaching AIDS (by TeachAIDS organization)	Why it is socially acceptable:  Curricula presents HIV/AIDS prevention material while decoupling it from traditional sex education (may enter into areas where sex education is banned or considered sensitive).  Campaign materials based on both what public health officials consider important as well as needs identified by target population (through baseline surveys).  Characters designed to suit cultural likes and dislikes (e.g. costumes).  Character voices selected to reflect Indian accents (selected by target audience).  Script adapted to incorporate colloquial phrases (piloted and iterated based on feedback from target audience).  Culturally-appropriate metaphors and euphemisms (piloted	Why it is accurate/complete:  ICT-based curriculum delivers exactly the same information every time.  Materials vetted by numerous medical and health professionals.  Cultural euphemisms and metaphors tested on target population to ensure they are communicating the correct messages.  Alternate and novel concepts around teaching about HIV/AIDS prevention materials tested on students to ensure efficacy in learning.	Learners can utilize the materials in private or semi-private contexts, and control the pace and flow of information.  Detailed information can be provided in a full-tutorial context, as opposed to piecemeal approaches of most mass media campaigns.  Materials developed based on iterative design process (piloted on hundreds of students in India) to test the learning, retention, comfort and overall efficacy of the learning materials. Summative and formative based on target audience were developed and used.  Use of pedagogically-grounded strategies and communications theories to improve	Why it's easy to deploy:  Free software has zero marginal distribution cost when used through the Internet, and minimal cost of production on CD. Materials from CDs can be installed on numerous computers.  May be administered regardless of teacher's previous knowledge.  Learning materials can be deployed using various technologies, depending on local context (computers, mobile devices, project with large screen). May be viewed regardless of Internet connectivity.  Materials can be used in conjunction with other materials or as a stand-alone mass communications tool.  Materials scalable to small or large

and iterated based on feedback from target audience).  Male and female specific version to accommodate gender preferences and empowerment.  Materials available in multiple languages to suit local audiences.	learning and retention (e.g. mnemonic devices, voice interfaces)	audiences (use of computer or PDA for one-on-one interaction or projected to numerous people at the same time, which may be most useful in resource-poor locations.  Animations contain subtitles for hearing impaired and audio for preliterate learners to ensure greater access to the materials.
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#### 5.2 Success of Interactive Teaching AIDS

A large-scale study was conducted using the *Interactive Teaching AIDS* application in September, 2007 on 386 young adults in India. The study found statistically significant gains in learning (*p*<.001), retention (*p*<.001), and changes in attitudes (greater acceptance of HIV/AIDS-related issues and people) (*p*<.001). Furthermore, 98.6 percent of the participants felt comfortable learning from this tool and 94.5 percent said that they learned more about HIV/AIDS through this animated tutorial than any other communication method, including television or school. Perhaps the most remarkable result was that, although it was related to numerous taboo subjects, almost all of the young adults were willing to forward the tutorial to others and wanted to learn more about HIV/AIDS. One month after initial exposure to the tutorial, students were rapidly seeking out and educating others about HIV/AIDS prevention through peer networks, with nearly all of them sharing information learned from the tutorial with someone else (Sorcar, 2009).

The success of *ITA* led to the development of TeachAIDS, a California-based nonprofit aimed at providing research-based, culturally-appropriate HIV/AIDS materials for learners around the world. The theory, methodology, and development process outlined have been extended to create learning applications for people of diverse cultures. TeachAIDS has partnered with numerous governmental agencies and non-governmental organizations, and research institutions to develop and launch customized applications. Outside of India, TeachAIDS has had great success in launching interactive animated materials in around the world including South Korea, Rwanda, South Africa and China, among others. The campaigns have been so compelling that in 2009 numerous A-list celebrities (e.g., Shabana Azmi, Amol Palekar, Akkineni Nagarjuna, among others) joined the TeachAIDS efforts and gifted their voices to the animated works to expand the reach even further.





Left: The Canadian International Development Agency (CIDA) uses TeachAIDS.org materials for their Rural Health Education Project in Goa, India. Right: High school students at Oakland International High School in California, United States, using TeachAIDS.org materials as part of their comprehensive lessons on HIV/AIDS awareness and prevention strategies.





Left: Students at Central Johannesburg College (CJC) in South Africa working on TeachAIDS.org baseline study. Right: Youth at Stepping Stones International in Botswana interacting with TeachAIDS.org applications.

## 5.3 Theoretical, Empirical, and Methodological Contributions

With the success of this approach, there is great potential to change the way educators think of addressing and delivering this form of education entirely. Regardless of the ban on sex education throughout India and the cultural sensitivities around discussing this across the globe, a way to provide education for all was discovered, regardless of their cultural norms and social contexts. This same methodology can be, and already is being, extended to other contexts where taboo topics hinder the effective dissemination of education for potentially life threatening conditions.

#### Theoretical Contributions

Determining effective methods to openly discuss and educate about sensitive issues, while encouraging learners to feel safe and communicative, remains a tremendous challenge for communication experts (Benton & Daniel, 1996). Research indicates that most taboos are inextricably linked with the various transformations of the human body (e.g., disease, death) (Allan & Burridge, 2006), making these issues particularly difficult about which to educate. Numerous studies have shown that teachers themselves can be reticent and uncomfortable providing sexual education to their students (Nayak & Bose, 1997; Verma et al., 1997). Although these challenges exist, there is little, if any, guidance on how to develop effective materials for taboo topics. This research will significantly contribute to the literature around best practices to teach about

sensitive subjects. The theoretical framework identifying the challenges in teaching about communication taboos has been coupled with the framework for evaluating multiple dimensions and efficacy of such targeted curricula with a successful exemplar that future researchers can draw and build-upon to enhance effective communication, particularly in education and public health related fields.

Communicating learning from this new approach is especially important since evidence shows that it is possible to effectively teach about sensitive issues without disrespecting or challenging cultural beliefs and norms. Unlike other HIV/AIDS curricula, which are based on biomedical approaches (highly technical) or teach avoidance of particular activities to prevent danger (e.g. "Just Say No" campaigns, abstinence-based sex education), this method incorporates the pedagogical and cultural advantages of each. On one side, students are receiving the scientific knowledge in a way they understand and are able to build on prior knowledge, furthermore extend it to novel contexts. On the other side, stakeholders remain highly comfortable with the message itself and its delivery. If the results from this study are any indication of future possibilities, a theoretical framework has been unveiled, which researchers, communications experts, and educators can extend to other challenging and sensitive contexts (e.g., Hansen's disease, formerly known as leprosy).

#### Empirical Contributions

The empirical findings will contribute to the literature around the complex relationship between knowledge and attitudes. Furthermore, they will help in understanding the differences between these relationships for different cultures, socio-economic classes etc. Using a similar pattern to develop rigorous measures, outcomes can be determined in other Asian and African countries, which face similar challenges as India around discussing HIV/AIDS issues publicly.

Furthermore, porting this curriculum to other contexts and media (e.g. mobile devices, flip-charts, cartoon books, video) to measure the efficacy of using these platforms to spread awareness can be explored. This is especially important since, despite obvious need for this education, not all communities have equal and unlimited access to technology. Alternate media and distribution channels have differing advantages and disadvantages in terms of access, ease-of-development, ease-of-use, cost, efficacy, and other factors (see table 36). Further research will need to be conducted in order to determine the true cost/benefit analysis of these models.

Table 4. Advantages and Disadvantages of Different Media

Medium / Channel	Description	Advantages	Disadvantages
Flash	PC, advanced mobile device-based distribution	Interactivity, Internet-based tracking, rich user interface	Access limited to those with funds and access to PCs and Internet or very sophisticated mobile devices
Java	Intermediate mobile distribution	Improved access over Flash version, private learning environment	Limited UI, difficult to port animation, most mobile devices in India and other developing nations not supported

SMS	Widespread mobile distribution	Universal mobile access, private learning environment	Requires reimagining of curriculum to work through an SMS UI, SMS costs money
Audio	Mobile / landline telephone distribution	Universal telephone access, private learning environment	Requires reimagining of curriculum to work through audio UI, calls cost money
Book	Cartoon books, textbooks, flip-charts	Near-universal access (assuming literate and preliterate versions), storyboard will generally translate well to a book	No interactivity or trackability, high distribution costs

#### Methodological Contributions

Arguably one of the most significant contributions of this work is its provision of an understanding of the process of development of such a tool. Using the framework and following the documented step-by-step process will help experts extend these lessons to other contexts.

This chapter outlines two tiers of methodologies that can be followed. First, there are the more broad concepts. These would include lessons such as conducting assessments to identify the source of the taboos, understanding the cultural challenges, assessing various methods to deliver curricula, and iterative testing and development, among others. The second tier includes more specific strategies to appropriate an application, including selection of proper voices, suitable graphics, culturally appropriate analogies, mnemonic devices, and colloquial passages. Together, these strategies can inform the design of more effective interventions.

#### 5.4 Scalability and Diffusion of Innovation

The diffusion of innovations theory (Rogers, 1995) concerns how new technology spreads through cultures. With the success of this exemplar, curricula like the ITA application can be disseminated through informal and formal learning environments. Informal learning environments would include museums, Internet, mobile devices, or by NGOs or other outreach organizations developing HIV awareness campaigns.

Formal learning environments would include school-like facilities. Scholastic environments are ideal vehicles for dissemination of accurate and comprehensive HIV/AIDS related information and have been identified by experts as appropriate places to undertake such activities (Kirby, Short, Collins, Rugg, Kolbe, Howard & Miller, Sonenstein & Zabin, 1994; SIECUS, 1999).

First, involvement in and attachment to school and plans to attend higher education are all related to less sexual risk-taking and lower pregnancy rates. Second, students in schools with manifestations of poverty and disorganization are more likely to become pregnant. Third, some school programs specifically designed to increase attachment to school or reduce school dropout effectively delayed sex or reduced pregnancy rate, even when they did not address sexuality. Fourth, sex and HIV education programs do not increase sexual behavior, and some programs decrease sexual activity and increase condom or contraceptive use. Fifth, school-based clinics and school condom-availability programs do not increase sexual activity, and either may or may not increase condom or contraceptive use. Other studies reveal that there is very broad support for comprehensive sex- and HIV-education programs, and accordingly, most youth receive some amount of sex or HIV education. However, important topics are not covered in many schools. (Kirby, 2002)

Because this tutorial does not incorporate explicit images or educate via traditional sex education, its likelihood of acceptance among Indian schools and other informal structures is greater. Also, locating critical information within ICT allows educators to comfortably facilitate and/or augment the learning process and alleviates pressure to deliver accurate medical content and feelings of embarrassment or uneasiness. Outside of these physical environments, it can also be disseminated via the Internet, including social networks like Facebook and Orkut, popular among young learners.

The next stage in scaling this solution is to create a collaborative system to allow participants from around the world to contribute to developing new curricula. This would be a web-based system much like Wikipedia, except with structured data and processes to allow for staged development and high levels of quality control. High quality, verified content is a requirement for any health-related curriculum. The creation of this system will not only allow for the creation of more effective curricula, but it will also allow those curricula to be developed and iterated upon more quickly than ever before. This is particularly advantageous in dealing with possible future public health outbreaks along the lines of conditions like SARS.

#### 5.6 Conclusion

The successful outcomes of the Interactive Teaching AIDS intervention on hundreds of young adults in India, and the subsequent launching of the highly successful TeachAIDS nonprofit, has demonstrated that it is possible to create an effective communication messages despite the challenges in educating about taboo topics. Tools like the ITA application can be disseminated through formal and informal learning environments, depending on where it is most suitable. Because these applications do not incorporate explicit images or educate through traditional approaches, they have been acceptable in various institutes and other organizations around the world. Using these lessons, reticent educators can more comfortably facilitate the learning process without the pressure of delivering accurate medical content, while minimizing feelings of embarrassment or uneasiness. Furthermore, such applications can be administered as a standalone learning tools or used as a supplement to an existing curriculum. Experts can use canned versions irrespective of their previous knowledge or extend modules using the similar methodologies.

Building on previous theoretical and empirical literature, a framework of evaluation, outlining critical issues to consider has been introduced, while designing effective materials to best educate on taboo topics. Combining the flexibility of ICT-based applications with culturally-appropriate learning materials, experts can develop tools which both maximize learning and simultaneously work within existing cultural norms and traditions. Through the dissemination of effective and carefully crafted messages, TeachAIDS? hopes to provide open access to prevention materials and improve the lives of individuals around the world.

#### List of References

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