

# From Intervention to Outcome: The Relationship between Knowledge and Behavior in a Trachoma Control Project

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## Abstract

The fundamental problem for evaluating social health interventions is the relationship between the health promotion effort, behavior change, and subsequent disease outcomes. Trachoma, *Chlamydia trachomatis*, an infection of the eye, is the leading cause of preventable blindness in the world. Trachoma is hyper-endemic among the rural population of the Egyptian Delta. From 1990 through 1991 an Egyptian–American health intervention was conducted to increase the number of children who had their faces washed with soap and water at least once each day, a behavior known to reduce the risk of active infection.

The research design of this intervention allowed us to determine the levels of change in beliefs about the cause and possible prevention of eye disease, active and passive knowledge about face washing, and actual behavior change. The project demonstrated large changes in knowledge and attitudes resulting from the intervention. These changes indexed smaller changes in passive knowledge and still smaller changes in behavior. These small behavioral changes, however, were shown to be statistically significant in reducing children's risk in the target village, where the risk for active infection was decreased by a third.

*Keywords:* Trachoma, Behavior Change, Egypt, Intervention, Health Promotion

## Introduction

Health education, leading to the adoption of healthier behavior, is perhaps the most frequently used model of public health promotion. Despite its popularity, the relationships among knowledge, attitude, behavior and disease reduction are not fully understood. The transtheoretical model developed by Prochaska and his colleagues (Prochaska & Velicer, 1997) moved the understanding of these relationships forward by setting out stages through which individuals move from pre-contemplation to enacting the behavior. Contemporary neuroscience and psychological studies have addressed the link between knowledge and behavior by analyzing motivation, such as presented in Jonah Lehrer's (2009) book, *How We Decide*. But, as a host of recent studies attest, behavior change interventions are fraught with difficulties in moving from imparting knowledge to changing the outcome of the disease or condition under study (Boden-Albala, Carman, Moran, Doyle, & Paik, 2011; Gkeredakis et al., 2011; Heinrich, Maddock, & Bauman, 2011; Owens, Jones, & Nash, 2011; Stuart et al., 2011; Sun et al., 2011; Takemura et al., 2011). Many of the cited studies beg the question of disease change altogether by claiming success through changed intentions, or changed risk perception.

Evaluations of health interventions can more directly ask a set of four questions with regard to measuring the change in disease prevalence: Can it work? Does it work? How does it work? Is it worth it? (Bartholomew, Parcel, Kok, & Gottlieb, 2001; Cochrane, 1972; Haynes, 1999). Changing individual or group behaviors are the main goals of many health interventions. Some consider behavioral change the "central outcome" of health interventions, especially in primary prevention (Kaplan, 1990, 2000).

Answers to the question, "Can it work?" can be found in theoretical analyses, from preliminary empirical observations, or both. By showing that changes in the epidemiology of a disease result from the intervention, a carefully designed, community-based health intervention can answer the question, "Does it work?" (Shadish, Cook, & Campbell, 2002).

Answers to the question, "Is it worth it?" depend upon a variety of practical, financial and political considerations that factor into decisions as to whether or not to use a proven intervention on a broad scale.

It is much more difficult for interventions that seek to change health related behaviors to answer the question, "How does it work?" (Øvretveit, 1998). Assessing behavior change outside of the laboratory can be very difficult, as appropriate evidence is sometimes

impossible to gather, or can be gathered only indirectly (Michie & Abraham, 2004: 36). Moreover, “proper interpretation of the evidence depends on the availability of descriptive information on the intervention and its context” (Rychetnik, Frommer, Hawe, & Shiell, 2002:119). Behavior change is especially difficult to assess because the evaluation data can often only be obtained from self-reports or other indirect proxy measures. This makes it especially difficult to know whether any behavior change or outcome attributable to the intervention, including any the theoretical models of change on which the intervention was based, is truly responsible for that change.

This paper looks at the relationships among knowledge, attitude, and health outcomes in a study of trachoma in the Egyptian delta. A logistic regression analysis, which controlled for the seasonal variation of eye disease, showed that the intervention over one year was successful in reducing the risk for active infectious disease among children in the intervention village by a third (OR = .675, 95% CI .460, .989,  $p = .043$ ). The intervention was developed based on ethnographically-derived, culturally-valued health behaviors in the community (Lane, 1987), and using local cultural materials.

The findings of this study, together with other similar studies of face washing, and studies of oral azithromycin for the treatment of trachoma (e.g., Dawson et al., 1997), formed the basis of the SAFE strategy (surgery, antibiotics, facial cleanliness, environmental improvement) used by the International Trachoma Initiative’s strategy to eliminate blinding trachoma by 2020.

The intervention design and results are presented in detail elsewhere (Rubinstein et al., 2006), but before turning to examine the relations among self-reported behavior change and observed behavior change in the intervention, it is useful to provide some background context.

### Face-Washing and Trachoma

Trachoma is a chlamydial infection of the eye and is the leading cause of preventable blindness in the world. Recent estimates indicate that trachoma is “responsible for 1.3 million cases of blindness ... [and] is endemic in 55 countries, mainly in Africa and Asia” (Polack et al., 2005:913). Infection with the bacterium *Chlamydia trachomatis* leads to inflammation of the upper eyelid. Clinical diagnosis of active trachoma is made following detailed World Health Organization criteria in which the inner upper eyelid is examined under  $\times 2.5$  magnification. The clinical severity of trachoma is graded according to the number and size of follicles observed on the conjunctiva and the inflammatory thickening of the tarsal conjunctiva (Bird et al., 2003:1670). Those infected by *Chlamydia trachomatis* do not develop immunity to the organism, and thus can be re-infected, perhaps multiple times. Following active infection, scarring of the conjunctiva results when the follicles and swelling resolve. Active infection and inflammation can lead to permanent conjunctival scarring. Severe and repeated scarring of the eyelid can make the inner eyelid contract and turn inward, causing the eye lashes to rub against the cornea. Overtime, this painful condition can also cause the cornea to become opaque, resulting in loss of visual acuity, eventually leading to blindness.

Active trachoma infection is seen mostly among children. For example, in the Egyptian Delta, research showed that the prevalence of trachoma among the population

declined sharply after children reached fourteen years of age. Although active infection is largely a disease of childhood, the scarring and blinding consequences of trachoma infection mainly affect adults.

In conjunction with on-going United States–Egyptian research on blinding eye disease in the Egyptian Delta, Sandra Lane conducted ethnographic research on eye disease in a Delta hamlet. During this work, she made systematic observations of a sample of households that indicated that children that had their faces washed once a day with soap and water were at considerably reduced risk for having active infectious trachoma (Lane, 1987: 179–201). In contrast with other studies (e.g., Taylor, Velasco, & Sommer, 1985), only face washing with soap and water (as opposed to with water alone) provided a protective effect.

In addition to these empirical observations, there were convincing theoretical reasons to think that community-wide efforts to promote face washing could change the epidemiology of trachoma. Theoretical models of trachoma transmission based on animal and human studies (Forsey & Darougar, 1981; Salim & Sheikh, 1975) suggested that flies formed an important vector for the transmission of trachoma, especially in environments that lacked basic hygiene infrastructure (e.g., Courtright et al., 1991), because they spread the ocular secretions from eye to eye.

But, would promoting face washing on a community-wide basis work more broadly to decrease active infectious trachoma? To answer this question, the Francis I. Proctor Foundation of the University of California, San Francisco in collaboration with the University of Alexandria Medical School, and the High Institute of Public Health, in Alexandria, Egypt, proposed to demonstrate the efficacy of a community-based health intervention to promote face washing. We integrated the standard Knowledge, Attitudes and Practices (KAP) measures (see, e.g., Manderson and Aaby, 1992) into a data collection form that also drew on anthropological interviewing techniques and Lane's insights into the ethnomedical ideas about eye disease in the Egyptian Delta. Further details of these materials and of the research design of the intervention are available in Rubinstein, et al. (2006).

Prior to undertaking the intervention, a survey was made of villages in the Delta. The project epidemiologists and ophthalmologists visited a dozen villages during which they surveyed the environmental context of the villages and screened children for trachoma. All children diagnosed with trachoma infection were treated. The villages, which were all small communities (approximately 1,500 individuals) related to a larger administrative town, were included in the survey if they had roughly equal sized populations, similar access to water, and similar socioeconomic levels of development. We used this survey to identify four villages for the study. There were no statistically significant differences among the four in their environmental circumstances, size, socioeconomic status, and background rates of eye disease. One village was used as a setting in which researchers were trained and tested their research instruments. For the other three villages to be used in the study, we conducted in depth environmental surveys which allowed us to compare villages on a wide variety of environmental variables. After this environmental assessment we conducted statistical analyses to ensure that the villages were comparable on environmental factors that might affect eye disease. The three villages selected for the study showed no statistically significant differences on the environmental factors.

From the environmental surveys, we can characterize the villages in the following ways: All of the villages were farming communities without running water piped to the homes. Rather, each village had a common standpipe from which villagers could draw water. All adjoined canals the water from which villagers used for a variety of activities, including dishwashing, laundry, bathing and recreation. The walls of the houses in the villages were largely constructed of concrete brick while the floors of the houses were packed dirt. The houses typically had one or two rooms for use by the family, and nearly all of the houses in each village had an attached animal room in which the family's large animals could be kept. Animal manure is an important source of cooking fuel in the Delta and large dung piles are owned by families and kept near their homes. Although homes were built near one another, the villages had open public spaces and spaces between houses.

Statistical analysis of the pre- and post-intervention data controlled for seasonal fluctuation of eye disease. We also controlled for the potential bias of "Hawthorne effect" (see also, Shadish, et al., 2002; Wolfe & Michaud, 2010) by having a two intervention villages: one village with an intervention aimed at increasing face washing with soap of children and the second village in which an intervention of equal effort, but focused on activities that would not affect trachoma, were conducted. At the start of the study, children in the two intervention villages and the control village were examined by ophthalmologists, who diagnosed those with trachoma. There were no statistically significant differences among the three villages in the proportion of children with trachoma infection; all children in the three villages with trachoma infection were treated. At the end of the one year intervention period, the village with the face washing showed one third fewer trachoma infections among children, compared with the "Hawthorne" village. Thus, the community-wide face washing intervention reduced risk of active infectious trachoma by a third.

### Measuring Knowledge and Behavior

The behavioral change that the intervention sought to promote was at least once daily face washing with soap and water of children aged 10 and younger. The intervention promoted face washing, and the risk of active infection declined. It is reasonable to interpret the decline in active trachoma in the intervention village as the result of behavior changed by the intervention. But, we wanted to know in greater depth exactly how this success was achieved.

The pre- and post-intervention questionnaires we used elicited self-reports about three different kinds of knowledge, attitudes and practices. We call these "passive knowledge," "active knowledge," and "specific beliefs," each which we discuss below. In addition, the study design included direct observation of face washing behavior among a systematic sample of households in the intervention village, the "Hawthorne" dummy intervention village, and the control village. This allowed us to examine how the reduction in active infection was achieved.

#### *Knowledge Self-Reports*

For the pre- and post-intervention questionnaires we used a basic ethnographic interviewing technique that invites the person interviewed to define the range of information to be considered. In our intervention study, the interviewer asked each mother, "What kinds of problems can happen to your eyes?" This kind of question, which is referred to in the anthropological literature as a "Grand Tour" question (Spradley, 1979: 62), allows an

open ended response, and gives the person interviewed a chance to use their own knowledge to outline the domain. In our intervention this question invited the enumeration of any ethnomedical eye problem. Our questionnaire form included space for a dozen ethnomedical eye conditions that had been described by Lane (1987) in her health ethnography, as well as opportunity for other volunteered responses.

Any eye condition elicited through the grand tour question required that the mother being interviewed volunteer this knowledge. Because her response was unprompted, we call the information elicited through the grand tour question an instance of “active knowledge.” Active knowledge is a report by the informant of some aspects of her world that are salient to her, without prompting.

### *Specific Beliefs Regarding Behavior*

Ethnographic interviewing techniques also include in question frames that elicit smaller domains of knowledge. These kinds of questions, which are called “Mini Tour” questions, ask “an informant to describe some smaller unit of an event or activity” (Spradley, 1979: 63). Such questions also elicit active knowledge, but the information elicited is about a restricted range of information. During the interviews, we asked mothers to respond to two mini tour questions that described their belief and behavior about face washing. These questions “How many times per day should children’s faces be washed?” and “With what should children’s faces be washed” give us information about specific practices that mothers self report.

### *Passive Knowledge*

The very last question asked by our interviewers was “Have you ever heard of trachoma?” (The actual question was “Have you ever heard of Ramad Hubaybi?” Ramad Hubaybi is the Egyptian Arabic medical term for trachoma.) Since the response to this question required no active response on the part of the mother being interviewed, the answer to this question represents a relatively passive pool of information. For this reason we call this “Passive Knowledge.”

### *Observed Behavior*

It is something of an anthropological truism that what people say they do and what people actually do are not always the same. Indeed, systematic studies of informant accuracy “show that informant reports of behavior are incorrect about half the time, but that the distortions are highly patterned” (Trotter II & Schensul, 1998: 719). When Lane (1987) interviewed families about face washing of children with soap and then conducted direct day-long observations in the same families she found that there was approximately 28% difference between what mothers reported doing and what they were observed to do. The uncertain accuracy of self-reported data is a problem faced by epidemiology as well (Hulley, Cummings, Browner, G., & Newman, 2007: 43). The bias inherent in informant recall, and the frequent disparity between normative and actual behavior, means that during fieldwork anthropologists gather information about what people do through a variety of methods and measures. This practice, which is an example of “triangulation” (Rubinstein, Scrimshaw, & Morrissey, 2000; Trotter II & Schensul, 1998), resonates with Campbell’s and Fiske’s (1959) advice for increasing validity in quantitative research design.

For this reason, the data collection for our intervention study included two periods of direct observation of face washing behavior. For these “observational family studies” a researcher observed the children in 15 households. The researcher, who was trained in systematic observation of behavior (Johnson & Sackett, 1998), spent six hours in each household during which she used the time allocation method to count the instances of children having their faces washed with soap and water. This allowed us to cross-check reported behavior with actual behavior.

### The Face Washing Intervention

The face washing intervention took place over one year. During that time the face washing intervention village received information about trachoma and face washing through several modalities (for details of the intervention see, Rubinstein, et al., 2006).

Families with children 10 years and younger received periodic visits from local community health workers. These visits were more frequent during the early part of the first months of the intervention than during the rest of the year. During these visits health workers conveyed information about trachoma and its transmission.

The community health workers distributed bars of locally produced, and inexpensive, soap to families with children 10 years and younger on a bi-weekly basis. Soap distribution took place throughout the year-long intervention (Figure 1).

Posters encouraging face washing were posted strategically throughout the intervention village. These posters were hand painted in a style that mimicked the genre of local cinema advertisements, which earlier research had suggested would be effective in conveying other kinds of messages to the villagers.

A song patterned on standard folk melodies was created. This song described the transmission and effects of trachoma, and encouraged face washing. The song was taught to school children. During the intervention year, singing the song when community health workers or the project researchers visited the village became a kind of competitive game for the village children.

The final part of the intervention involved the creation of a puppet show about trachoma and face washing. This puppet show was patterned on a traditional cultural way of spreading news (and often political messages) called an *arragoz*. The puppet show was presented to an assembly of school children and their families.

### How the Intervention Achieved Success

We were interested in knowing how the intervention achieved its success. To trace the effects of the intervention we analyzed the changes that took place in each of the categories of information we collected through our questionnaires and observations.

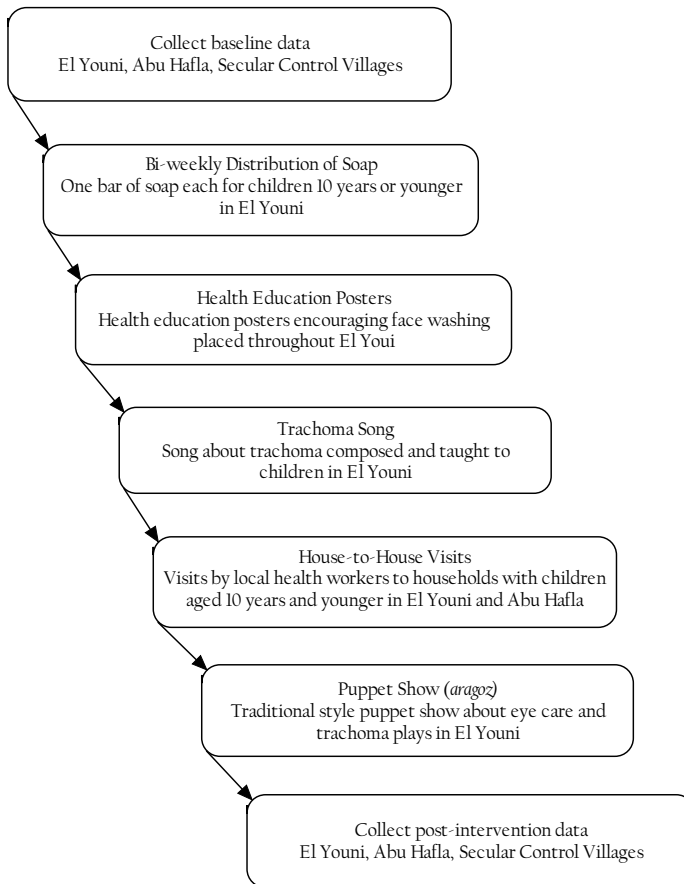


Figure 1. Elements of the Community-Based Face Washing Intervention

### Passive Knowledge

Prior to the start of the intervention there was no statistical difference in the proportion of villagers who reported knowing the term *ramad hubaybi*, the Egyptian Arabic term for trachoma. After the year-long intervention the “Hawthorne” villagers’ knowledge of the term had not changed, while 100% of the intervention village participants reported knowledge of the term ( $X^2 = 206.72$ ,  $p < .0001$ ). Of course, the intervention village experienced a frequent, multi-faceted, and year-long effort to increase knowledge of trachoma, so the dramatic increase is understandable.

### Active Knowledge

When asked “What kinds of diseases can happen to your eyes?” less than one percent of respondents in either the intervention or “Hawthorne” village volunteered *ramad*



*hubaybi*. At the end of the intervention, no one in the “Hawthorne” village volunteered *ramad hubaybi*, whereas 89% of those in the intervention village spontaneously mentioned the term ( $X^2= 207.99, p < .0001$ ). This finding indicates that *ramad hubaybi* was on the minds of those in the intervention village, at least when they were being interviewed by the research team (Figure 2).

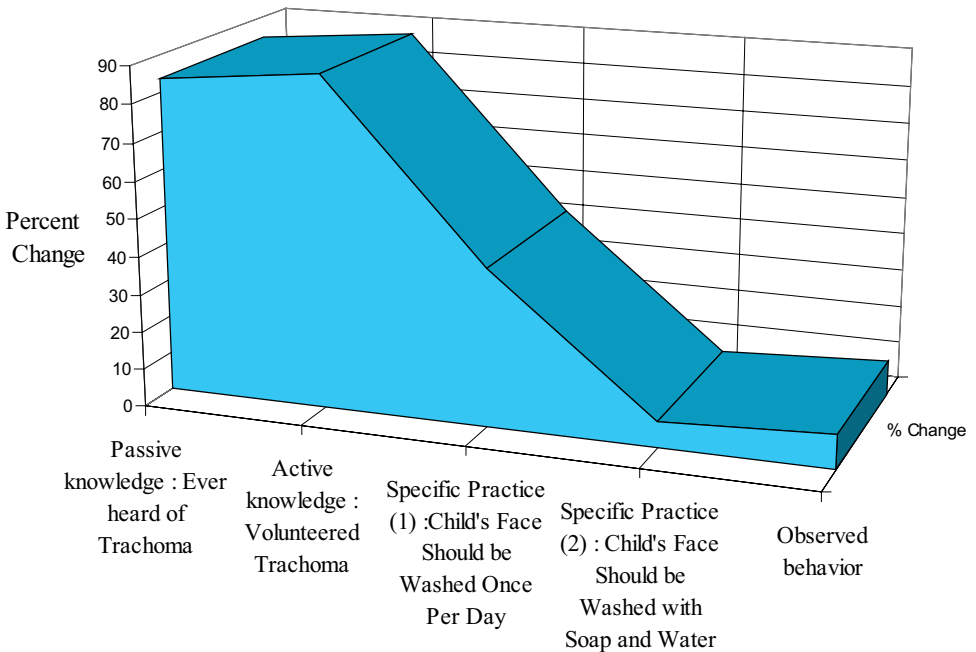


Figure 2. Change in Knowledge and Behaviors Attributable to the Face Washing Intervention

### Specific Beliefs Regarding Behavior

When asked “How many times per day should a child’s face be washed with soap” there was no difference between the answers of intervention or “Hawthorne” villagers prior to the study. At the completion of the study, the proportion of the intervention villagers whose responses specified the optimal number of face washings for children had increased by over 42% ( $X^2= 65.44, p < .0001$ ), whereas the “Hawthorne” group had not changed.

### Observed Behavior

In the observations conducted among families prior to the intervention no child face washing was observed in either the intervention or “Hawthorne” village households. In the observations at the end of the study still no children’s faces were observed being washed in the “Hawthorne” village. In the intervention village, 9% of the households children were observed having their faces washed with soap ( $X^2= 4.34, p = .037$ ). This is a relatively small change in behavior given the large changes in passive and active knowledge.

It may be that the six hour window of observation was inadequate to see all face washing. In Lane's study, she conducted observations from prior to sunrise, when the children were still asleep to after dinner, when the families were getting ready to retire for the evening. Even so, we were surprised to find that so much knowledge change had resulted in so little observed behavioral change.

## Conclusion

The intervention's success derives in part from the careful attention paid to the local cultural understandings about health in general and eye disease in particular. By incorporating these understandings into our KAP instruments we were able to design intervention activities that addressed trachoma in terms that resonated with the people to whom the intervention was directed. The intervention drew on several aspects of Egyptian culture, including film posters, song, puppet shows, and used locally available soap. The messages in each of those media were clear, consistent, and advised a specific practice ("children's faces should be washed with soap at least once per day") that could easily be accomplished. Those two points are critically important. It was clear from the feedback of villagers to the research team that they were amused by the children singing the trachoma song. The response to the puppet show was also warm and enthusiastic.

During the time of this intervention, there were numerous 30 and 60 second spots on Egyptian television advertising oral rehydration solution (ORS), to prevent childhood death from the dehydration that accompanies diarrhea (Lane, 1997). Similarly, the televised ORS spots had a song that ran with each spot. In both cases, however, a curious disconnect emerged. People who could sing the jingle—of the trachoma song or the ORS commercial—did not necessarily follow through with enacted behavior.

Our trachoma intervention changed knowledge dramatically, by nearly 100% for the term *ramad hubabyi*, a least as measured directly after the one year intervention. It also appears to have changed ideas about normative behavior, which is what people say that they should do. In interviews at the end of the intervention, overwhelming numbers of intervention villagers told the research team that children's faces *should* be washed with soap and water. Many even enthusiastically increased the proposed number of face washings, above that recommended by the intervention, to more than three times per day.

But when it came to actual behavior—the observed face washing of children with soap—the increase was much less. This common and frustrating finding stymies health educators, who reflect on, for example, the paradox of people who know that smoking is dangerous but who nevertheless take up smoking or those who know unprotected sex with a potentially infected partner can hurt them nevertheless fail to use a condom. *Knowledge itself does not always, or even frequently, lead to healthier behavior.* A famous study by Young (1981) called attention to this apparent disconnect. Young's study, titled "When rational men fall sick..." pointed out that we are not machines or, in modern terms, computers. Human behavior is motivated only in part by knowledge processed in the rational pre-frontal cortex of our brains (Lehrer, 2009). Other, less logical but more compelling sources of behavioral motivation arise from our emotional limbic systems that spew out desire, lust, anger, fear and envy. In this regard it is important to understand that there was a competing reason why

some parents kept their children's faces dirty (Lane, 1987), the cultural belief that envy that in the form of the evil eye can be a source of illness and death, as we discuss below.

Even though the intervention led to a large change in knowledge and specific beliefs about behavior, it led to relatively little actual behavior change (although the change that did take place had very important consequences). While such an outcome is consistent with findings from other efforts to change health behavior, as discussed above, there are some aspects of the Egyptian Delta villages that may help account for this finding.

All of the villages in the intervention study were farming communities. During the rainy season the villages are muddy and wet, while at other times they are dry and dusty. Thus, children's faces get dirty quite easily and keeping them clean is a chore, especially when clean water has to be retrieved from a common standpipe some distance from one's home. Keeping children's faces washed and clean can become a time consuming activity in a day filled with other work and obligations. This may be a negative reason for the small observed change in actual behavior.

Cultural understanding helped the intervention to succeed. At the same time, cultural beliefs may account for the small change in observed behavior. Dirty faces spoil the appearance of otherwise beautiful children, whose beauty might attract the *evil eye*, which is the covetous glance of an envious person. The evil eye is an important cultural category and disease explanatory concept for Egyptian villagers. The evil eye is considered as the possible source for all sorts of calamity, including illness. Villagers go to considerable lengths to avoid attracting the covetous attention that might lead to being the subject of the evil eye. It might be that some villagers in the post-test interviews were telling the research team what they wanted to hear, "yes we know that you think that face washing is important—we have been hearing you say so for a year." This would be then a case of the patterned distortion of self-reports noted by Trotter and Schensul (1998). But when a researcher was present in the home for observations, looking closely at the children only 9% had their faces washed. We think of direct observation as the "gold standard" for documenting behavior, but even this measure may be biased in ways that we cannot always predict.

Despite this small change in observed behavior, the intervention village showed a 33% reduction in infection after a year. In a sense, this result may be an example of the workings of the "Pareto Principle," which posits "that a small number of causes is responsible for a large percentage of the effect, in a ratio of about 20:80" (Hafner, 2001: para 2; first suggested by Vilfredo Pareto in his study of wealth distribution, see Pareto, 1964 [1896]). In our case, a year-long health education intervention yielded modest observed changes in behavior, but rather large changes in disease prevalence. This finding is similar to that of the Egyptian diarrheal disease control program, which found that diarrhea deaths were cut in half despite numerous studies that demonstrated that ORS was not appropriately used. We can only speculate on what happened. Perhaps, with the distribution of free soap and the health education about the links of blinding eye disease with face washing there was more face washing than we observed. Possibly, the families whose children had red and runny eyes did the most face washing. Nevertheless, a small behavior change resulted in larger than expected disease change.

Consistent with earlier findings concerning health behavior change, the face washing intervention produced large changes in knowledge and attitudes and much smaller changes in actual behavior. The reasons for these observations may be broadly applicable to other intervention efforts. On the one hand, barriers to health behavior change may result from potential environmental barriers to that behavioral change, and, on the other hand, culturally validated reasons for not changing health behavior may limit the change that takes place. In our own research we are incorporating designs which allow the parsing of these two types of barriers to change (e.g. Lane et al., 2008). A broad range of health interventions should give consideration to designs that allow researchers to map both the constraints on behavior change that result from structural barriers and those that are motivated by the social and cultural contexts in which they take place. Such designs can produce data that may then be used to revise interventions to emphasize areas that promote success in changing behavior, thus making them more effective.

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