Psychosocial self-assessments of HIV prevention behaviour and perceptions of risk in multiple cultures.

Lawrence J. Severy, Betsy Tolley and Greg Guest
Family Health International

The Behavioral and Social Sciences division of Family Health International is currently engaged in a series of investigations all relevant to the topic of self-assessments of risky behavior, in a variety of cultural contexts. Many of these studies are being conducted in conjunction with Phase II and/or Phase III randomized controlled trials of new microbicide products designed to prevent HIV/AIDS. Other studies, in yet other cultures, are specifically focused upon the identification of optimal procedures for obtaining the most valid and reliable self-report information from HIV prevention trial participants. In totality, there are ongoing studies in more than a dozen countries. It should also be acknowledge that there is often as much cultural variation within countries as between countries. Most of our studies also pursue the male partners of women participants. Not only does this allow, for the investigation of gender differences in perspective, but it also allows for a form of data collection triangulation to better assess the behavior of couples and the reasons for their behaviour.

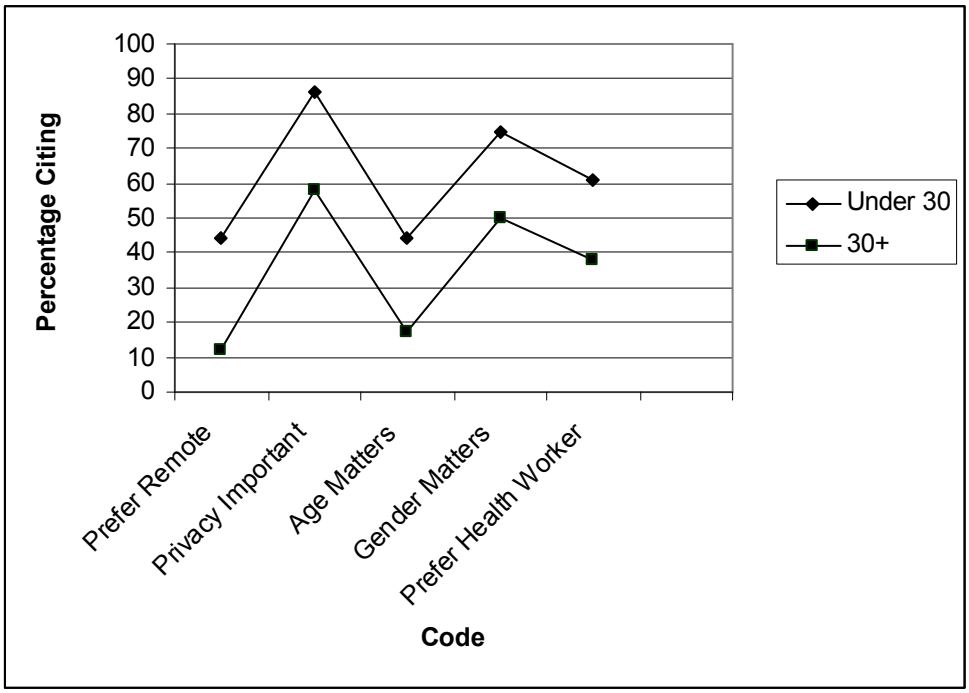
The microbicide clinical trials involve three different initiatives, in three sets of countries. To start, community preparedness and ongoing acceptability studies were conducted in Ghana, Nigeria, Cameroon, and Malawi – all attached to an investigation of the use of oral tenofovir as an "oral microbicide" to prevent HIV. A second set of countries, including Benin, Burkina Faso, Uganda, South Africa and India, are engaged in a clinical trial of Cellulose Sulfate as a topical microbicidal gel to prevent HIV. Our main activity in this trial is to assess differing community preparedness for such a trial, and the development of appropriate recruitment strategies so as to attract the correct trial participants. In this case, the predominant parameter in identifying the "correct participants" is that related to finding those participants who will display a level of risk and consequent incidence of HIV to allow for a comparison between the arms of the RCT. Hence, measurement of risk and prevention behavior is of paramount importance. A final trial, comparing two additional microbicide products (Buffergel and PRO2000), is planned for yet another Indian site.

It is the case that in all of these sites, no matter what the specific focus, we have been engaged in the pursuit of methods and assessment devices designed to identify perceptions of one's prevention behavior in juxtaposition to their perceptions of personal risk. It is clearly the case that such reports are often at odds with epidemiological data on such prevention behaviors and the prevalence of risk in the various communities. In fact, what tends to happen in these trials, at least as observed in many trials, is that the incidence of HIV infection in the trials is much lower than published prevalence rates would suggest for the exact same population (or subpopulation). The paradox seems to be that the very fact of being in a trial tends to have a public health impact – perhaps due to the attention and care provided to participants, if not the result of making participants

actually think about their behavior – while creating troubles for the statistical power of the trial based upon the original prevalence statistics. One performs such trials so as to eventually impact public health, but the result is that those in the trial (all arms) seem to benefit immediately. It also makes suspect our ability to assess such behaviour.

Another programmatic effort has specifically targeted the problem of the validity of such self-reports, and the optimal strategies for obtaining accurate information. These studies, mostly qualitative in nature, have been conducted in Zimbabwe, Nigeria, Ghana and Botswana. Working mostly with participants who had earlier been involved in now terminated clinical trials, discussions focused upon whether there were reasons to not be truthful during the trial (as regards their risky behavior), whether there were methods that might have teased out the truth, and recommendations that the participants had for improving the entire endeavor relating to risky behavior, self-reports, and the conduct of trials. For example, Guest and colleagues (2005) conducted in-depth interviews of 60 women in both Ghana and Nigeria to assess their perspectives on the task of self reporting risky behaviour. The women were specifically tasked with the chore of identifying how they would suggest that we ask their best friends about risky behavior and prevention behaviours. All data were subjected to formal analyses. A variety of themes resulted. Specifically, women generated concerns for: privacy, age of the interviewer, gender of the interviewer and preferences for a health worker. Most importantly, women wanted us to know that discussions of HIV create fear, and that interviews need to be sensitive to the context in which these women are living their lives. Figure 1 displays the relative importance of some of these factors contrasted by the participant's age. The figure is adapted from the Guest et al, 2005, article.

Figure 1. Thematic expression by age.



Perhaps our most comprehensive study involves the preparation for a clinical trial comparing two microbicides, mentioned above, and being conducted in Pune, India. There have been two phases to this initiative. The first involves the generation of a multidimensional self-assessment tool (or interview tool) that assess various components of risky behavior, perceptions of prevention, and potential impact on the personal and relationship (including intimate) lives of the respondents. Having conducted multiple focus groups, individual interviews, item generation, translations and back translations to Marahti, we have collected pilot data for scaling purposes from 300 India women and 150 of their male partners. We hope to compare the internal structure of these assessment devices as a function of gender, as well as substantive differences in the scale scores as a function of gender. In turn, these scales will be utilized in a prospective study of women (and their male partners) in microbicide trials about to begin in Pune. We will be able to track perceptions of risk over time, for those in the trials and their control groups.

A challenge for those measuring a behaviour that involves two people is the decision the scientist must make regarding the situation when the two assessments do not match. And, often male and female partners do not report the same information or scores on scales. As Miller, Severy and Pasta (2004) have argued elsewhere the mathematical combination rule one adopts reflects differing psychological assumptions about couple dynamics and decision-making. For example, simply averaging or totaling the responses imposes equal influence. Calculating the absolute value of the differences places more focus on consensus than the relative value (high versus low) of the score. And, taking the high score as representative of the couple would indicate a belief that the "champion" for a position is a more precise couple score in comparison to a low score "veto" power being more accurate. A question for future study is which of these various procedures will best correspond to epidemiological data and statistical parameters reflective of any study population.

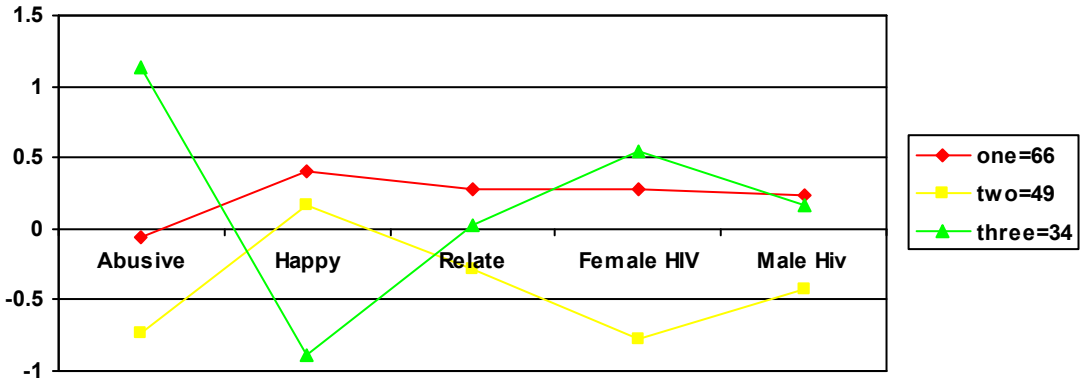
More specifically, the following parameters related to engaging in prevention behaviors were investigated in the Pune, India, investigation: HIV risk perception – including knowledge, severity, feelings of susceptibility, denial and stigma; and couple harmony – including sexual pleasure, emotionality, decision-making interdependence, partner support, sexual faithfulness, and commitment. In addition, self-reports of sexual activities and prevention efforts are also obtained – from both the woman and her partner. Our analyses of the data generated by the 450 above described participants continues. However, our preliminary findings are provocative.

Figure 2. depicts the results of a cluster analysis of the 150 couples with data provided by both the husband and the wife. These couples were recruited from the same geographic and demographic populations that are selected for the microbicide clinical trials. It is fair to suggest that they represent a lower middle class group from within the Pune area. As can be noted in the graphic, three different groups empirically clustered together. These represent about 40%, 33% and 20% of the study population.

The groups of clusters were then depicted on a number of the scales and items assessed during the study – so as to profile the differences. By the nature of the statistical

procedures that we used, we know that the groups must be statistically significantly different on the vast majority of the dimensions depicted. The factors depicted include an abusive relationship, a happy marriage, commitment to maintaining the relationship, the woman's degree of concern about HIV and the man's degree of concern about HIV.

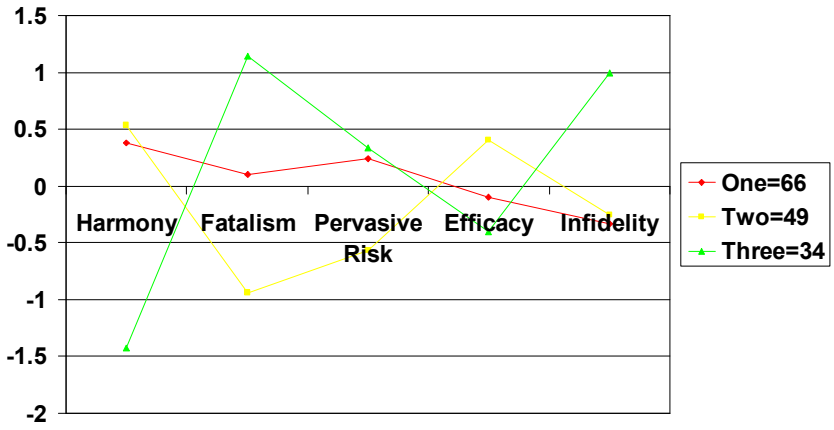
Figure 2. Profiling three "market segments" of trial participant couples in Pune, India.



As can be noted, cluster one depicts what is probably the normative or typical couple, and the group was the largest in size. Abuse was about in the middle of the z score range, and happiness and commitment to the relationship were above average. The woman and the man acknowledge that HIV is a problem. Cluster two is either in denial, or they have a great relationship. The low scores for HIV concern demonstrate this group's overall perspectives. Lastly, those in cluster three display a dysfunctional relationship with abuse, unhappiness, the woman "knowing" that they should be worried about HIV and the male rating this concern to a lower degree. There are many implications for clinical trial success in these groups, and observation of incidence either very different from, or surpassing, prevalence statistics for Pune.

In figure 3, only the women's data are presented. The findings are generally the same, but the obvious problems of the third cluster are amplified. Specifically, it is clear that women in this group strongly suspect that their partners are engaging in risky behaviour with multiple partners.

Figure 3. Women's scores on multiple dimensions related to their relationships, their perceptions of HIV risk, and their ability to do anything about their situation.



Our goal for this presentation was to engage in an activity analogous to a meta-analysis of our work in order to make observations and offer speculation as to the lack of correspondence between behavioral assessments versus the more epidemiological or demographic accounts of risk in a community. And, it was also our intention to bring a gender lens to the discussion