Community Based Research Activities for AIDS Control

Lilarani Swain[1], Sravanthi Mettu[1], Vineeta[1], Sanghamitra Mohanty[1], Dharitri Samantaray[1], Leena[1]

[1]*Rourkela Senior Nursing College, Sambalpur University, Odisha, India.*

Corresponding Author: drleena222@gmail.com

Abstract: This article reports on a study into the extent to which individual participation in community participatory research actions on HIV. In this research, cultural compromise analysis was used in an exploratory manner to measure the level of agreement among participants prior to and immediately following contribution in community participatory workshops. The results demonstrate changeability by community and gender in the levels of consensus, or agreement, achieved through the workshops. These findings suggest that consensus is not an automatic outcome of participation in small group interventions and in some cases can result in less agreement on community issues around HIV. Also discussed is the potential utility of cultural consensus analysis as a tool in evaluating the effectiveness of community participatory interventions.

Key Words: *—HIV, Hispanics, cultural models, consensus, community.*

I. INTRODUCTION

Over the past decade, a rich literature has developed on community-based participatory research approaches to preventing morbidity and mortality from human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) in diverse communities [1]. Studies to date have involved African American, Hispanic, Asian/Pacific Islander, and white persons in the U.S., gay and bisexual men, intravenous drug users, sex workers, migrant workers, urban and rural residents, at-risk youth, and people from several countries around the globe. An increasing number of CBPR studies on HIV/AIDS prevention have used faith-based intervention approaches involving people identified through church congregations [2]. Community-based participatory research methods are particularly useful for studying ways to prevent morbidity and premature mortality in population subgroups that are marginalized, stigmatized, or discriminated against in society, or who are otherwise unempowered [3].

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For example, CBPR approaches have been employed for health promotion research conducted in African American and Hispanic communities that face barriers to stopping the spread of HIV related to socioeconomic issues (for example, poverty and limited access to quality health care and education), distrust of the health care system, language barriers, and cultural differences from other groups that are targeted by service providers. Community participatory research is a cover term for a range of contextually directed interventions that involve community members in addressing problems at a local level. Generally, these interventions attempt to engage members of the community in the research process to produce information for programme planning and to stimulate critical awareness and reflection among community members about the issue or problem targeted for change [4-6]. The current diversity of research activities described as participatory often makes establishing bounds around these research activities difficult [7]. As Minkler and Wallerstein (2003) note, action research, participatory research, collaborative action research and participatory action research are all titles given to various modes of research that potentially fall under the more general rubric of community-based participatory research [8]. Despite growing interest, limited research has gone into understanding the micro-structural changes promoted through the small-group processes that form the core of most community participatory activities [9]. Too often, users of participatory methods state that the aim in using such methods is to empower participants, while lacking a means of measuring changes fostered through such activities. This is particularly

true in developing-world settings where such methods are often used without necessary technical and programme resources [10]. To date, most studies that consider the consensus aspect of community participatory research activities have examined the quality of partnerships and have not looked at the quantity of agreements that results from such collaboration in the research process [11]. Theoretically and methodologically, this research draws on the field of cognitive anthropology in conceptualising and measuring group agreement. Cognitive anthropology, the branch of anthropology concerned with how humans think and organise their world [12]. In particular, the analytical procedure of cultural consensus analysis can be used to measure levels of agreement between groups of workshop participants prior to and after participating in the community HIV/AIDS prevention workshops. Cultural consensus analysis, a non-probabilistic mathematical procedure for measuring the level of agreement among a set of informants on elements of cultural knowledge, is based on individual responses to a set of structured questions that refer to a single cultural domain [13]. A particular strength of using consensus analysis is that it uses local community concepts, identified through ethnographic research, in evaluating agreement. This contrasts with other methods used in considering group performance in the participatory process in that it does not rely on outside or subjective measures or scales used in efforts to examine dimensions of participation [14]. The prevalence of HIV infection in adults is 15 per cent and reaches as high as 30 per cent in distinct populations such as sex workers and perinatal clinic attendees in urban settings. Multiple partnering and transactional sexual exchanges are contributing to the continued spread of HIV/AIDS, particularly among 14- to 29-year-olds. Because there is no cure and treatment are available to only a small portion of the population, preventing the spread of the HIV virus remains essential for lessening its impact [15]. Because heterosexual intercourse is the principal mode of transmission, much of the prevention effort has focused on modifying sexual behaviours to reduce individual risk of infection. Most interventions focus on increasing individual knowledge concerning the disease and promoting personal methods of risk reduction, such as abstinence and condom use. However, the continued spread of the virus suggests only moderate success in meeting the challenges of HIV/AIDS in this setting. A particular challenge to addressing HIV/ AIDS in many African nations is a lack of community recognition or dialogue on HIV/AIDS and its related issues. Almost twenty years after the first case of AIDS was diagnosed [16].

II. COMMUNITY ACTIVITIES

The 'Drama Dialogue Planning and Production Model' which provides the setting for exploring the dimension of agreement in community participatory research, was a pilot effort to combine traditional methods employed in participatory research, such as community mapping, visual diagramming and role plays, with drama planning and production skills in a set of community workshops [17]. In responding to a lack of awareness and dialogue on HIV/AIDS issues in the community, as identified by a local AIDS organisation and the sponsor of the community participatory research activities, the aim was to create a cohesive community intervention that leveraged local knowledge and understanding of HIV/ AIDS causality with a popular form of communication for the purpose of increasing or promoting HIV/AIDS prevention and care in communities [18]. In each village, it took approximately six weeks to complete four full-day workshop sessions, to complete one half-day workshop session and to plan and implement the community drama presentation that made up the 'Drama Dialogue Planning and Production Model'[19]. The workshops started with visual diagramming activities, such as free listings, rankings and flow diagrams, where workshop participants identified and assigned values, in terms of severity or importance to community, to issues related to HIV/AIDS [20]. For this exercise, workshop participants were asked to identify some of the different community or social factors contributing to HIV/AIDS problems in their community; then the participants worked together to organise and show relationships between the various factors [21]. The activities were done using sheets of paper on the floor of a community household. After identifying and considering both ramifications of and solutions to the issues affecting each village, the groups were presented with the overarching task of putting on dramas depicting local issues (e.g., orphan care, couple counselling and testing, and discordant couples) to share information and understanding gained through the research process [22]. In total, sixty-one individuals participated in the workshops from the four collaborating villages. Of these, twenty-nine were men, and thirty-two were women.

III. METHODS

To gauge whether changes in agreement as to community HIV/AIDS priorities occurred among members of the communities participating in the participatory activities, the overall analytical process of a cultural domain analysis (CDA)

was followed. Cultural domain analysis is a systematic process for eliciting categorical data from members of a group that can be analysed quantitatively to identify patterns or relationships in the responses [23]. The general steps followed were to (1) elicit from members of the community the content of a cultural domain concerning issues key to HIV/ AIDS; (2) ask members of the community to organise the domain, consisting of different associations or relationships between domain items, through a method of systematic data collection; and (3) better visualise the structure of the domain through data-reduction methods. Consensus analysis belongs to the third step of cultural domain analysis in that, along with other data-reduction techniques such as multidimensional scaling and cluster analysis, it helps us visualise (2) the structure or organisation of a domain--consensus is concerned with the extent to which domain items and attributes are shared. In this research, consensus analysis provides a way to compare pre- and post-measures of group agreement as to priority or importance of key issues concerning HIV/AIDS in the community. In eliciting a domain of HIV/AIDS, members from a community were asked about the problems HIV/AIDS was causing in their community; key informant interviews were used to determine the specific issues related to AIDS in the overall community [24,25]. The specific interview format used was in-depth, open-ended interviewing. The sample of individuals interviewed comprised both a convenience sample of community members and others selected based on occupational and social criteria, such as teacher, health worker, and traditional healer [26]. Through this interview process, participants identified and discussed a range of biological, social and cultural issues relating to the spread and impact of HIV/AIDS. Some of the issues identified through the interviews included the availability and use of condoms, the practice of widow inheritance, the actions of young people involved in transactional sex, the role of family and parents in discussing HIV/AIDS, the willingness of couples to receive HIV testing, the acceptance and protection of orphans, alcohol use and risk, and the role that famine and poverty play in peoples' HIV/AIDS risk [27]. From analysis of interviews, we developed a list of sixteen HIV/AIDS-related concerns and issues in the community. Domain items included such statements as 'Men and women look for partners other than their spouse' and 'Condoms are not being used in preventing AIDS' [28]. In eliciting a domain of HIV/AIDS, members from a community were asked about the problems HIV/AIDS was causing in their community; key informant interviews were used to determine the specific issues related to AIDS in the overall community.

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The resulting eigenvalues of the factor analysis are used to determine if a single cultural rationale is responsible for the patterning in the response data [33]. By convention, if the first eigenvalue, which represents an underlying cultural rationale used in ranking the items, is three times that of the second eigenvalue, one concludes that there is significant consensus among the group [25]. The factor loadings from the first factor of the factor analysis also provide a measure of each informant's agreement with the overall model provided by the group. This number functions as a type of competency score for each individual in regard to their individual knowledge of the cultural shared domain being analysed. In addition to conducting the pre- and post-surveys, and similarly to an approach used by Mathews (2000), we used observation to further understand how workshop interactions potentially fostered the development of new, shared understandings concerning AIDS in each of the four research communities. Notes were taken on the information produced by groups in conducting the participatory research and on the groups' interactions during the workshop [27].

IV. Results and Discussion

In the first two workshop groups, consensus was not found in either the pre- or post-rankings of domain items. In fact, there is an indication that the level of agreement actually decreased slightly after the workshop. This lack of consensus in the two communities suggests that the workshop participants did not view items elicited on AIDS concerns in the community as a coherent domain of items organised along a continuum of seriousness. However, in the last two community groups, the post-rankings show greater agreement among the informants. This is evident in the ratio of eigenvalue and in the high positive average competency score for the informants, which is another condition for consensus. This suggests the workshops were successful in increasing agreement among informants. In communities where consensus was not reached, review of individual competency scores among participants appeared to show that the majority of those with low scores were males. This prompted running the consensus analysis again, this time dividing the communities into two groups, men and women, for a total of eight pre- and post-groups [28]. Presently, this research suggests that increased consensus among individual groups is a possible outcome from the participatory research activities, but not a given. Additionally, tempering the finding of consensus in the two communities is the possibility of some kind of learning effect among the organisers of the sessions, which created the potential for greater consensus among those latter groups. Nonetheless, the findings from the cultural consensus analysis suggest some important considerations for using community participatory activities as consensus-building activities. Firstly, the results suggest a potential to influence consensus in a negative direction in terms of shared agreement [11]. In the case of the community findings indicate that group agreement was decreased among the group as a whole. More significantly, when examining agreement among the women in the group, we find a strong consensus among women in the group before the workshops. However, after the workshop, agreement among women decreased and failed to achieve the stated threshold for consensus. The participatory process may encourage the reevaluation of this model, with the result being that the participants develop a diversity of new concerns, particularly in relation to their own structural positions in society. Suggested then is a movement from some shallow, widely shared model to a more individually nuanced model for AIDS understanding, where forms of intra-cultural variation play a role in resulting agreement [15,16]. Either way, refining our understanding of the process of shaping agreement through further research could prove important to developing a better understanding of those for whom it is appropriate to employ similar community participatory techniques. Another finding concerns the role of group composition in whether consensus is achieved among a group. When analysis was conducted along gender lines, consensus is found among only two of the female groups. when the men's rankings were removed from the model, consensus remained but was slightly diminished. Further, the other group to demonstrate consensus with both men and women, consensus was no longer achieved when men were removed from the consensus analysis [17]. In this instance, men's views were important to reaching agreement within the group. These findings from the gendered analysis suggest a need for greater understanding of how communication within and between sexes may promote or inhibit the promotion of agreement within groups. In addition, this leads to consideration of power and differential access to or sharing of community knowledge. One possibility in interpreting the results, which is perhaps supported by the history of these communities, is that women, through purposeful engagement or more general engagement in health activities, have developed a more defined domain for considering HIV/ AIDS-related issues [18]. In particular, the history of engagement of these communities in prevention activities should be considered in light of the gender analysis.

V. CONCLUSION

This research suggests the use of cultural consensus analysis as a tool for understanding the participatory process in communities. Ultimately, however, for cultural consensus analysis to have utility for this kind of research, levels of agreement or consensus must be linked to health outcome measures, both in terms of discrete HIV/AIDS prevention efforts and long-term contributions to the health of a community [34]. Is higher consensus on community health issues beneficial to promoting health-improving activities in communities? If so, which consensus conditions provide the greatest benefits? To further understand the utility of this approach to evaluating community participatory research, more research is needed that includes more communities and multiple measures of consensus on related health domains to provide a more accurate picture of agreement in terms of health and community knowledge. Work must be done to control for differences between communities in evaluating and understanding consensus change, to better understand the conditions that promote or hinder community agreement [35]. Likewise, repeated measures of consensus need to be made to determine the stability of changes in community agreement. Again, these measures of agreement need to be linked to both short-term and long-term measures of health in communities. Foremost, this research did not address the outcome measures necessary to form such conclusions, since collecting outcome data for evaluation purposes was beyond the scope of this research [32]. Further, the type of change we are discussing is often slow and systemic, requiring both longitudinal data collection and a variety of methods to detect subtle changes in a community. Challenges to measuring outcomes, however, should not discourage us from future work in this area. Given the intensive work required to evaluate community-directed efforts in health promotion, if consensus were found to play an important or positive role in changing communities, methods to measure consensus could serve as an important mediating or intermediate variable in evaluating community efforts.

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