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ENGAGING THE COMMUNITY IN HEALTH RESEARCH IN INDIA

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Abstract

Community-engaged research approaches involve members of the community in various aspects of a research endeavor to improve the health of populations. Engaging the community in research is important in the development, dissemination, and evaluation of new interventions, technologies, and other medical advancements to improve population health globally. A review of published community-engaged research studies conducted in India was performed. Fifteen published studies were identified and reviewed to evaluate the state of community-engaged research in India. The review indicated that community-engaged research in India is limited. Most published community-engaged research focused on health promotion, especially in the prevention or management of HIV/AIDS and other STIs. Community members were involved in a variety of aspects of the research, but there was not one published article indicating that community members had defined the disease of focus. Community-engaged research often led to valuable insights into the views, experiences, and behaviors of community members and also led to increased community participation in health initiatives. It is anticipated that future community-engaged research will lead to improvements in global health through increased empowerment of communities and a better ability to implement new and innovative medical advances, technologies, and interventions.

Keywords

Community-engaged research; Participatory action research; Community-based participatory research; India; Public health

INTRODUCTION

Each day brings new medical advancements and technology that improve the prevention, diagnosis, treatment, and survival for countless diseases. These medical advancements and

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the research to develop or evaluate new technologies would not have been possible without the active participation of members of various communities. However, the benefits of medical and technological advancements are not realized by all populations globally. This is especially true in resource-limited countries, like India, where adoption of these advancements is slower due to multiple factors, such as the high costs of medical care to patients and families and health care systems with constrained resources (2). When resources exist to provide high-quality medical care to populations in resource-limited countries, sometimes there is a lack of adoption by some communities and individuals, leading to disparities in health outcomes. Therefore, community engagement is critical to the development as well as global implementation of innovative medical advances and technologies.

There are a number of different terms to describe research that involves community engagement: empowerment evaluation, community action research, participatory action research, participatory rural appraisal, and community-based participatory research (CBPR) (1,3,24). Engaging the community in a research partnership is important since it is widely recognized that health and disease are influenced by the environment in which a person lives (13). The environment is broadly defined to include the social environment, the physical environment, and the culture of the community. Without an understanding of the context of health and illness of individuals and communities, it is difficult to create practical and relevant strategies to enable community members to obtain high-quality medical care or engage in healthy behaviors (23). Learning more about community members' beliefs, values, preferences, and health behaviors is important because it allows for the better development of health interventions that work within the context of community members' culture, belief systems, or preferences for learning new information. Although there are many conceptualizations and models of community-engaged research, it is generally agreed that a health promotion program should be delivered through multiple levels, including individual behaviors, interpersonal relationships, community, and society, and it should be delivered in a manner that avoids exploitation and community disruption (13,23). Engaging the community to improve outcomes for a particular health problem targeting multiple levels may reduce health disparities.

Research designs vary on a continuum corresponding to the degree of decision making and direction provided by the community and the researchers, ranging from a "researcher-driven" approach to an approach with full participation of the community. In a researcher-driven approach, the researcher retains most of the power in the research process and determines all aspects of the research from beginning to end with no community input, including the topic of research, study design, data collection, analysis, interpretation, and dissemination. At the other end of the continuum are approaches like CBPR, which "equitably involve all partners in the research process and recognize the unique strengths that each brings" (15). Full community participatory approaches, like CBPR, emphasize equity in the collaborative process of research and a relationship built on respect, trust, and mutual benefit (23). Each partner takes part in every aspect of the whole spectrum of the research process from defining the problem to planning for sustainability of the intervention (11,24). Although CBPR is advocated as a research strategy that is mutually beneficial to both researchers and community members and that improves community capacity and involvement (25), it is not fully clear whether the approach leads to better health outcomes. In a review of interventions designed using CBPR, studies that utilized a randomized controlled trial design indicated a positive effect on health (9). Those studies that utilized a quasiexperimental design had mixed findings (25).

Community-engaged research approaches are prevalent in countries with more resources, like the US and Canada. However, the approaches are less often used in other areas of the world, making them more novel and innovative globally (23). To date, there has been no

known review of community-engaged research in India. It has been noted that there is a lack of community needs assessment as well as community participation in the development and implementation of health education programs in India (19). Accordingly, the objective of the present article is to describe the state of the science of community-engaged research in India. To accomplish this objective, we conducted a narrative review of published articles describing the use of research methods that engaged the community to address health problems in India. Similar to a previous review of CBPR research (25), we sought to answer the following questions. 1) What health problems have been addressed using community-engaged research in India? 2) What populations have participated in community-engaged research addressing health issues? 3) What is the purpose of community-engaged research in India? 4) How have community members contributed to and benefited from the research process? 5) What are the benefits of using community-engaged research designs to address health problems in India? 6) What are the barriers to conducting community-engaged research to address health problems in India? Obtaining this information allows us to describe the scope and characteristics of community-engaged research in India.

METHODS

A search of PubMed was conducted using the terms “community-based participatory research” and “India,” along with an additional free text search using Google. Additional articles were reviewed from reference searches of qualifying articles. Studies were included if they: 1) were conducted in India, 2) were conducted to address a health problem, and 3) engaged members of the community in the research process. One study author reviewed all abstracts for relevancy. Three study authors reviewed relevant articles to address the research questions of interest.

RESULTS

Fifteen studies were identified by the various search methods (4–10,12,14,16–18,20–22) (Table 1).

Health Problems

The articles revealed that community-engaged research was most often conducted to address prevention and management of human immunodeficiency virus (HIV), acquired immune deficiency syndrome (AIDS), and other sexually transmitted infections (STIs) (4,5,12,17–20,22). Community-engaged research was also used to improve waste management (21), improve health care seeking for sick infants (8), evaluate low rates of health care utilization (16), improve menstrual hygiene (7), assess the needs of the community regarding cervical cancer prevention and management (6), and evaluate issues related to improving the quality of life and quality of care of people with disabilities (10,14).

Populations

Most of the community-engaged research studies reviewed involved adults (4,9,17,18,20,22), with a few studies including adolescents (10,12). Some studies focused on improving the health and wellbeing of children and adolescents specifically (7,8,10). Males were targeted in two studies (9,20), and females in four studies (6,7,17,18). The most frequently studied and engaged population was sex workers, who participated in the efforts of research described in three studies (4,5,22).

Purpose of Research

While four articles only focused on assessing the needs or views of the community (6,9,10,16), in several other articles community-engaged research was implemented to

facilitate the planning of an intervention program for disease prevention or management (7,8,12,14,17,18,20,21). Some studies also implemented the intervention (7,8,20). Only a few studies focused on the evaluation of an intervention implemented using community-engaged research (4,7,8,22).

Partnerships and the Role of the Community

There were a variety of partnerships described in the research reviewed. Partners in community-engaged research described in the articles included community members and organizations (4,5,8,21, 22), a tribe (16), academic institutions (4,5,7, 8,10,14,16–18,22), health professionals (6,14), governmental organizations (21), and nongovernment organizations (6,10,12,14). Academic partners included researchers from universities in Canada, Europe, and the US (4,5,10,14,16–18,22), a medical institute in India (7,8), and researchers from India whose institutions were not identified (5,14). Sources of funding were identified in 12 articles (5–8,10,12,16–18,20–22). Funding agencies included Indian government agencies (12,21); Canadian government agencies, corporations, professional organizations, and universities (10,16); US government agencies and organizations (7,8,17, 18,20,22); universities and government agencies in the UK (5,12); and other international organizations (7,8,12).

The role of community members in each research project described varied widely. Since many articles provided a snapshot of one small part of a larger research or intervention collaboration, it was not fully clear whether community members were included in past or future aspects of the research (12,14,18,20,21). None of the articles described the community as being pivotal in defining the problem of interest. Some studies reported a more limited role of community in the particular aspect of the project that was being described, typically as participants in some type of needs assessment focused on a particular health issue (14,21) or on health in general (9). For instance, one article described how community representatives participated in a Strengths, Weaknesses, Opportunities, Threats (SWOT) analysis in preparation for the design of a solid waste management program (21). Other types of community participation included roles of leadership in the project, such as serving on a Community Advisory Board or as part of a community organization (5,17,18,22). Community members also assisted in the development of focus group guides (17,18) or the interpretation of focus group results (18).

In other articles, community members participated in activities related to a health intervention or program, such as intervention development, implementation, or evaluation (4,5,7,12,17,20,22). Usually community participation in the needs assessment phase occurred before “mobilization” of community members to address the health issue (7,8,20,21). In various articles that described the Sonagachi Project, a community participatory and empowerment project among sex workers, community participation went beyond trying to change individual behavior of sex workers related to HIV and other STI prevention. Instead, activities also focused on empowering the sex workers to advocate for their profession, improve their political power, and reduce their societal and occupational vulnerability (4,5,22).

Benefits of Community-Engaged Research in India

From researchers’ perspective, there were a number of benefits to engaging the community in research. Often cited in the articles reviewed were the surprising and valuable insights into the views, experiences, and behaviors of community members obtained during community-engaged research (7,9,12,14,16–18,20). For instance, one article describing an evaluation of the perspectives of implementing a lay health worker program among women living with HIV/AIDS found that women perceived that having a lay health worker visit

would be a source of stigma (18). Formative research to design a HIV/AIDS/STI preventive intervention found that men reported fears of semen loss from masturbation (12). Educational information addressing these fears was added to the HIV/AIDS intervention, which may have improved community members' understanding of the topic. In addition, three interventions that used community-engaged research were associated with improvements in health knowledge, health seeking behaviors, and condom use (4,7,8,22). However, some of the research projects evaluating the efficacy of these interventions had significant design limitations, like small sample sizes and no randomization.

From the communities' perspective, there were several benefits to taking part in research. Participation from the community often resulted in recommendations of including further community engagement and participation during intervention development (16,21), as well as activism to improve access to care and other health resources (9). For instance, in an article describing a SWOT analysis, the findings indicated that certain members of the community (youths, "housewives," and senior citizens) could play a pivotal role in the implementation of a successful waste management program (21). Sometimes community participation in a needs assessment resulted in community members becoming more engaged with the health issue that was the subject of the needs assessment or participating in more community activities (7,14,20). In addition, initiatives that engaged the community in research addressed other problems faced by the community. One article reported that in addition to focusing on the reduction of HIV and other STIs, the Sonagachi Project provided microfinance services and programs to increase literacy among the sex workers. The Sonogachi project also worked to increase the political power of the community and to obtain services and education for the sex workers' children (4,22).

Challenges in Community-Engaged Research in India

Several articles mentioned challenges of conducting community-engaged research in India. One article, which reported on experiences with a project focused on improving the health of sex workers, indicated that there were challenges in working with groups and individuals who were interconnected in the lives of the sex workers, but who also exploited them (5). These people and groups had mutually beneficial relationships that centered around economic and physical security and political gain. These relationships required much effort to cultivate and maintain in the face of changing environmental and societal conditions.

In addition, because the sex workers were a marginalized and impoverished group, there was a strong need to have health professional partners who could advocate on their behalf using their political power. These health professionals also provided management and leadership skills in the initial years of the project until members of the community were ready to assume these roles. While this community engagement process began with health professionals at the top of the hierarchy, it was gradually transferred to people in the community. Thus, equity in leadership came over time as the sex workers developed managerial and leadership skills. However, other research utilized naturally occurring social hierarchies to communicate prevention messages by training men identified as "opinion leaders" to provide factual information about HIV prevention (20).

There were some logistical challenges mentioned in the delivery of a community-engaged intervention or in the implementation of a needs assessment. Some challenges were noted in the training of community members to deliver health promotion interventions, including low literacy among community members (20). In addition, one article described multiple issues related to the implementation of a community participatory needs assessment (14), including participants' frustration answering research questions and conflicts of the research design with communal cultural norms.

One more challenge to community-engaged research projects was the dependence on outside funding and assistance for sustainability (5). Many of the community groups targeted are marginalized and impoverished and have minimal ability to generate funds to support initiatives. Therefore, these community members rely heavily on a network of insecure and competitive funding agencies and donors to sustain their projects. In addition, some funding agencies have their own agendas with regards to the focus of the funding they will provide. While there are times that the community and the funding agencies agree on the focus, at other times they diverge. Because of the reliance on outside funding, the projects have to produce deliverables, like reports which require additional staff time and effort. In addition, project staff is needed to regularly publicize the project to attract funding (5).

DISCUSSION

The purpose of the present article was to describe the state of the science of community-engaged research in India. Community-engaged research is an important and innovative technique that may mobilize communities to improve global health. However, the results show that the use of community-engaged research approaches in India is limited. Most of the existing community-engaged research was conducted to support health promotion initiatives. It appears that it is feasible to engage various Indian communities to support health promotion initiatives, but evidence for the success of the health promotion initiatives developed through community-engaged research is limited. Because it has been rarely used, the potential of this research approach has not yet been realized. Engaging the community in research in other disciplines, like biomedical research, technology research, or health policy research is important to more broadly evaluate the usefulness of the approach in India.

Our review did not restrict research by the type of disease or population of focus, but our findings indicate that most published articles focused on the reduction and management of HIV/AIDS and other STIs (4,5,12,17,18,20,22), with a particular interest in the health of sex workers (4,5,22), and the health needs of adults (4–6,9,17,18,20,22). Of note, there were two studies that focused on improving the health of people with disabilities (10,14), but otherwise there has been no community-engaged research focused on other chronic conditions, nutrition, injury prevention, or other infectious diseases.

The articles reviewed indicate that there were many benefits to engaging the community in research, including the learning of new insights about the community. Sometimes these new insights helped facilitate the development of a community-engaged intervention. In addition, similar to the findings of Viswanathan et al. (25), the engagement of the community often led to community empowerment and generated a deeper interest in the health problem under study among the participants. This empowerment enabled community members to act upon other problems of interest to the community.

One interesting finding from the review of published articles was the fact that a number of academic researchers who partnered with various communities were from countries outside of India where community-engaged research is more common, like Canada and the US (4,5,10,14,16–18,22). There may be several explanations for this phenomenon. It may be that community-engaged research is not widely promulgated or conducted in India. Or, it is possible that community-engaged research activities that are currently being conducted, like outreach and community mobilization, are not considered as topics for publication or future research collaboration, and therefore do not appear in the literature. The high number of published studies from academic researchers from outside India may be explained by requirements of funding agencies. Most of the published research was funded, at least in part, by government agencies, universities, and organizations outside of India (5–8,10,12,16–18,20). Often funders require a publication as an indication of a completed

project, and so there may be more incentives for academic researchers outside of India to publish this type of research.

Although members of the community participated in various ways in the studies reviewed, we did not find any study reporting that community members had defined the health problem of focus. Several articles described research conducted in collaboration with the community; however, upon further examination, three studies indicated that community members only participated as research participants (9,14,21). On the whole, most studies reviewed indicated that there was a continuous sharing of information between the community and the academic researchers, with community members participating in leadership on the project, instrument design, or intervention delivery and dissemination (4–8,12,17,18,20,22).

The Sonagachi Project, as described in three articles (4,5,22), was the project that was most integrated in the community as indicated by reports of how decisions were shared and research processes implemented by members of the community. However, it appears that full sharing of power developed over time as the project became more embedded in the interconnected context of the community of sex workers and those who interacted with them. It took some time before the marginalized community became more empowered in the project and more able to fully share power with the other stakeholders. Although the Sonagachi Project was well integrated within the community, it still relied on the use of a hierarchy structure within the project leadership (5). Another project used a hierarchy structure to their advantage to deliver a health education intervention (20). These findings are interesting because they show the practical challenges of implementing a research paradigm that emphasizes equity in power and decision making in a culture that focuses on hierarchical decision making and power.

Another cultural aspect noted in a few studies was the challenge of promoting research and interventions focused on individual behavior change in the context of a communal worldview. Some researchers experienced difficulty with asking participants to take part in an individual interview as the participants felt more comfortable participating in an interview along with a friend or family member (14). Another study found that health decision making occurred in the context of the family, rather than as an individual behavior (9). One study (10) noted that community empowerment was more feasible when community members worked in small groups. Community-engaged research in India should consider the collectivist nature of Indian society, which values collaboration, interdependence, and shared benefits (9,10).

There are a number of limitations to this review. This is not a systematic review of the literature, so it is possible that eligible studies may not have been included in the review. Similar to the findings of Viswanathan et al. (25), there were not enough studies providing data on the efficacy of a CBPR research approach in improving health to draw any conclusions about whether the approach affects health outcomes in India. None of the studies obtained from the search involved full participation of the community in all aspects of a research project from identification of the focus of research to dissemination of the findings. In addition, this article does not include unpublished research or research that was not easily available in a PubMed search. This review does not compare the use of community-engaged research in India to other countries or other areas of the world.

This review of the literature points to several future directions. One future direction for community-engaged research in India is to increase the number of academic researchers from India who conduct and publish community-engaged research. In addition, another direction is to increase the participation of community members in all aspects of the study

from planning to dissemination of research data and beyond. Furthermore, the community-engaged research paradigm should be applied to other health conditions experienced by people in India as well as children, adolescents, and older adults. Increasing the number of high-quality intervention research studies that use community-engaged research approaches should also be a priority.

CONCLUSIONS

Innovative community-engaged research approaches are relatively rare in India. This review of research that engaged various communities in India to improve health indicated that this type of research approach has generally been limited to sexually transmitted diseases and the health concerns of adults. In the articles reviewed, there was a range of community participation in the research initiatives from minimal participation as the subjects in a research investigation to participation and empowerment in many aspects of the research. Engaging community members in research can prove to be a mutually beneficial experience for both researchers and community members and may have the potential to improve global health.

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Biography

Dr. Kristen J. Wells is an Assistant Professor in the Center for Evidence-based Medicine and Health Outcomes Research at the University of South Florida College of Medicine. She is also Assistant Member at Moffitt Cancer Center. Dr. Wells is a clinical health psychologist with a public health background who has extensive training in cancer prevention and control. Her research focuses on cancer health disparities, cancer health communication, and the development and evaluation of community health worker and patient navigation programs.

Dr. Charles Preuss is Assistant Professor in the Department of Molecular Pharmacology and Physiology, College of Medicine, at the University of South Florida. His scholarly interests are in medical education, pharmacogenomics, and nutraceuticals. He has taught pharmacology for over 9 years in several Colleges of Pharmacy and, most recently, has

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Dr. Yashwant Pathak is Associate Dean for Faculty Affairs at the University of South Florida College of Pharmacy. Dr. Pathak has worked in academics for over 15 years in various capacities—as Chair and Professor and later as Assistant Dean of Academic Affairs and Assistant Dean of Research. He is also associated with Nanotechnology Education and Research Center in College of Engineering and Translational Nano medicine Center in the College of Medicine. He has several years of Industrial experience. In fact, the last job he had was director of Research and Development for formulation and drug delivery systems.

Dr. J. K. Kosambiya is Professor (Additional) at the Department of Community Medicine (PSM), Government Medical College Surat, India. His research focuses on human immunodeficiency virus (HIV), acquired immune deficiency syndrome (AIDS), and other sexually transmitted infections (STIs) in vulnerable populations in Gujarat, India. He is currently the Principal Investigator for the project “Targeted Intervention among Female Sex Workers of Surat City.” Dr. Kosambiya also provides assistance in planning and implementing, monitoring, and evaluating various activities for the control and prevention of HIV/AIDS at the state level.

Dr. Ambuj Kumar is an Assistant Professor in the Division of Evidence Based Medicine and Health Outcomes Research, Department of Internal Medicine at the College of Medicine, University of South Florida. He also holds a faculty appointment at the Moffitt Cancer Center in the Department of Health Outcomes and Behavior. Dr. Kumar has successfully applied the principles of evidence-based medicine not only to the practice of medicine by constantly evaluating the evidence of medical interventions, but also has peer-reviewed funding for his work involving the same methodologies in research.

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Table 1

Published Community-Engaged Research in India

Ref.	Problem Addressed	Population	Research Design	Academic and Community Partners; Funding Agencies	Community Member Involvement	Benefits of Using Community-Engaged Research	Challenges of Using Community-Engaged Research
21	Municipal waste management	Lucknow, India	Qualitative: data collected through an activity worksheet	Community: governmental department, institutions, ministries, community representatives. Funding: Council on Industrial Research, Government of India	Participated in SWOT analysis to design a better program for waste management.	SWOT analysis indicated role of youth, housewives, and senior citizens was important and could be strengthened in the implementation of a waste management program.	
9	N/A	Men, rural Bengal, India	Qualitative: interviews with men	Not described	Participated in interviews	Learned people lack resources to purchase healthy food or go to a doctor when sick. Men would go to a "medicine seller" or homeopathic provider instead of a doctor. Trust in a provider is important. Family members are responsible to ensure the health of other family members. Political corruption is a barrier to health. State hospitals lack resources and supplies.	
16	Low utilization of healthcare	Paniya tribe, Kerala, India	Quantitative and qualitative: participant	Academic: University of Ottawa, University of Montreal, Centre for Development Studies, Community: Paniya tribe. Funding: International Development Research Centre;	Community as a whole provided informed consent to participate in the study. Community members participated	Approach provided rich information on poverty and health issues. Approach may have obtained data that could not be collected from a survey alone. Approach was rapid enabling researchers to quickly disseminate information to decision makers and stakeholders. Approach enabled investigation that was grounded in	Government healthcare is perceived to be poor. Paniyas feel marginalized by

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7	Menstrual hygiene	Female adolescents and young adults; Wardha district, Maharashtra, India	mapping, focus groups, in-depth interviews Quantitative and qualitative; data collected through surveys and focus groups	Canadian Institute for Health Research. Academic: Mahatma Gandhi Institute of Medical Sciences. Funding: Aga Khan Foundation; USAID.	in participant mapping, focus groups, in-depth interviews. Participated in needs assessment. Reviewed health education materials for refinement. Delivered educational program. Participated in evaluation.	the context of the community. Increased participation in community-based organizations. Increased participation in village-based health programs. Increased awareness of menstruation, use of readymade pads; decreased use of cloth. Increase in health-seeking behavior following symptoms of an STI or reproductive infection. Better understanding of target audience from needs assessment.	the larger society.
8	Infant health	Women, female adolescents, other members of community; Maharashtra, India	Quantitative and qualitative; data collected through surveys and focus groups	Academic: Mahatma Gandhi Institute of Medical Sciences. Community: 85 women's self-help groups; 20 <i>Kishori Panchayat</i> (forum of adolescent girls); 27 <i>Kisan Vikas Manch</i> (farmer's clubs); 20 Village Coordination Committees. Funding: Aga Khan Foundation; USAID.	Participated in formative surveys and focus groups. Reviewed health education materials for refinement. Selected and supervised <i>doot</i> (community health workers). Participated in newborn health education sessions. Participated in evaluation of the newborn health education program. Reviewed data collected during newborn health education program.	Women's participation strengthened their social and health insurance status. Women had more knowledge regarding newborn danger signs. There was an increase in seeking health care for a sick newborn.	
14	Disabilities	Ladakh, India	Qualitative: interviews with leaders, people with disabilities, and caregivers of children with disabilities; participant observation	Academic: Canadian rehabilitation professionals and researchers; Ladakhi researcher. American-Ladakhi researcher. Nongovernment organization: HEALTH Inc. Funding: Not described.	Participated in interviews	Community members became engaged in an issue which previously had received little interest. Researchers better understood issues faced by persons with disabilities, their families, and communities.	Community readiness questions were not well understood by research participants. Research participants had difficulty with visual scales. Ranking data was not valid and made people uncomfortable.

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10	Disabilities	Adolescents with disabilities, slums at outskirts of New Delhi, India	Qualitative: data collected through interviews, participant observation, focus groups, participatory development techniques, journal entries, interactions, daily observations, unobtrusive measures/outcroppings, document review, photos, videos	Academic: Queen's University. Community: ASTA, a local charitable trust offering community-based rehabilitation. Funding: International Development Research Centre; Queen's University; Canadian Occupational Therapy Foundation.	Participated in data collection. Reviewed data collected. Provided feedback on CBR documentation, annual plan, and annual report.		People were frustrated by repetitive questions. It was difficult to interview people alone as communities are very communal.
6	Cervical cancer	Females; Agra, Lucknow, Saharanpur, Uttar Pradesh, India	Qualitative: observation of 94 sites, in-depth interviews and focus groups with clients, community members, providers, policy makers	Health professional: Uttar Pradesh General Directorate of Family Welfare. Nongovernment organization: EngenderHealth.	Participated in team that reviewed literature and collected data. Participated in interviews and focus groups.	Found community members and clients lacked knowledge and awareness about cervical cancer and its prevention. Suggested that community leaders, nongovernment organizations, and community groups should help track women for follow-up care. Found community members were concerned about confidentiality. Found men were involved in the cervical cancer care process. Found a need to develop stronger linkages and referral systems to cancer treatment centers.	

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17	HIV/AIDS	Adult women (age 18 or greater) taking antiretroviral therapy; rural areas near Chennai, India	Qualitative: focus groups with women living with HIV/AIDS; health care providers, and Accredited Social Health Activists (ASHAs)	Academic: UCLA.	Participated in Community Advisory Board. Assisted in identifying women living with AIDS. Participated in focus groups. Refined interview guide. Helped shape the intervention program being designed.	Revealed several barriers to ART adherence including illness, financial, traveling long distances, lack of child-care, stigma, psychological problems. Found that social support would be beneficial. Women would like to receive care at the primary health centers closer to their homes.	
18	HIV/AIDS	Adult women (age 18 or greater) taking antiretroviral therapy; Chennai, India	Qualitative: focus groups with women living with HIV/AIDS; health care providers, and Accredited Social Health Activists (ASHAs)	Academic: UCLA.	Participated in Community Advisory Board. Reviewed focus group findings. Refined interview guide to ensure cultural sensitivity and linguistic appropriateness.	Discovered that having an HIV-trained ASHA visiting the homes of women living with HIV/AIDS may increase stigma.	
12	HIV/AIDS and other STIs	Adolescent and adult men and women; Gujarat, India	Qualitative: interviews, intervention flowchart data	Nongovernment organization: Deepak Charitable Trust.	Participated in data collection for intervention development and evaluation. Reviewed results of formative research. Provided outreach. Distributed condoms.	Broadened focus of an intervention focused on STI prevention to include a health concern identified by members of the community.	
5	HIV and other STIs	Sex workers, Kolkata, India	Qualitative: interviews (sex workers, non-sex worker professional staff, local people) and observations	Academic: European university-based researcher; Bengali researcher. Community: Durbur Mahila Smanwaya Committee (DMSC).	Participated in data collection. Participated in DMSC. Participated in local problem solving committees. Provided peer education. Distributed condoms. Made administrative decisions. Promoted social and political awareness.	Increased condom use. Sustainable program. Has mobilized the community. Sex workers have assumed some leadership for program.	Requires the development and management of relationships with other groups in the community that are interrelated to sex workers. Requires significant contribution of health professionals and funding agencies. Reliance on a hierarchy for decision making.

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22	HIV and other STIs	Sex workers, Kolkata, India	Quantitative: survey data collection	Academic: University of California, Los Angeles. Community: Durbur Mahila Smanwaya Committee (DMSC).	Provided peer education, social marketing about condoms. Provided supervision and program coordination. Provide leadership through the Durbur Mahila Smanwaya Committee (DMSC). Coordinate community organizing and mobilizing activities. Encourage political participation. Participated in data collection.	Increased knowledge of STIs and condoms as protection from STIs and HIV.	
4	HIV/AIDS	Sex workers, West Bengal, India	Quantitative: surveys	Academic: University of California, Los Angeles. Community: Durbur Mahila Smanwaya Committee, local community groups.	Provided peer education. Provided community organization, empowerment, and advocacy activities. Participated in intervention. Participated in surveys. Reviewed study protocols.	Intervention increased the number of sex workers who used condoms all the time.	Ethical dilemma—control community did not receive enhanced intervention.
20	HIV	Male alcohol users, Chennai, India	Qualitative: interviews with wine shop patrons and staff; participant observation in wine shops; field testing of training manual through focus groups		Participated in interviews and focus groups. Served as community popular opinion leaders to implement the intervention to peers.	Learned best ways to communicate prevention messages. Learned that training facilitators' ability increased over time. Learned how to handle important aspects of intervention implementation. Helped understand specific needs of target community, such as risk behaviors, their contexts, and barriers to changing them. Helped develop a relationship that was useful for implementing the pilot intervention. Helped ensure fidelity of the intervention.	Some community popular opinion leaders could not read well and had trouble understanding the training. Training facilitators could not answer some questions posed by community popular opinion leaders in training.