Collective Empowerment While Creating Knowledge: A Description of a Community-Based Participatory Research Project With Drug Users in Bangkok, Thailand

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In light of growing concerns regarding the ongoing drug war in Thailand and a lack of support for people who inject drugs in this setting, in 2008, we undertook a community-based participatory research project involving a community of active drug users at a peer-run drop-in center in Bangkok. This case study describes a unique research partnership developed between academic and active drug users and demonstrates that participatory approaches can help empower this vulnerable population while generating valid research. Further research is needed to explore ways of optimizing community-based participatory research methods when applied to drug-using populations.

Keywords community-based participatory research, injection drug use, Thailand, community empowerment

INTRODUCTION

Thailand has continued to prioritize an enforcement-based approach to addressing the harms of illicit drug use, which has led to mass imprisonment and severe human rights abuses of people who inject drugs (injection drug users, IDU) in the country, including extrajudicial killings (Beyrer et al., 2003; Hayashi et al., 2009; Human Rights Watch, 2004). Despite major successes in HIV prevention in Thailand through the “100% condom campaign,” the specific needs of IDU have essentially been neglected, and the continued severe marginalization of IDU renders it extremely challenging for this population to access essential public health and social services (Kaplan & Shleifer, 2007).

In response, in 2002, a group of active and former drug users united to form the Thai Drug Users’ Network (TDN) as a means of addressing the health and human rights concerns of Thai IDU (Kerr, Kaplan, Suwannawong, & Wood, 2005). The early work by the founders of TDN sought to expose Thailand’s human rights abuses of drug users and to protest the “war on drugs” policy. The activities of the network expanded significantly in scope in 2003 when it received funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM; Kerr, Kaplan, Suwannawong, Jurgens, & Wood, 2004). With support from the GFATM funding, TDN was able to initiate harm reduction projects across the country, including peer-driven HIV prevention and care programs.

However, despite the launch of this unique community-driven harm reduction initiative by the four grant recipients, we would particularly like to thank the staff and volunteers at the Mitsampan Harm Reduction Center for their support. We also thank Dr. Niyada Kiatying-Angsulee of the Social Pharmacy Research Unit, Faculty of Pharmaceutical Sciences, Chulalongkorn University, Bangkok, Thailand, for her assistance with developing this project. We also thank Daniel Miles Kane, Deborah Graham, Leslie Rae, Tricia Collingham, and Calvin Lai for their assistance with data management, and Prempreeda Pramoj Na Ayutthaya, Donlachai Hawangchu, and Puripakorn Pakdirat for their assistance with data collection. TK is supported by the Michael Smith Foundation for Health Research and the Canadian Institutes of Health Research. KH is supported by the University of British Columbia Doctoral Fellowship.

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recipients (TDN, Thai AIDS Treatment Action Group (TTAG), Alden House, and Raks Thai Foundation), scale-up of these and other harm reduction programs has been hampered by a lack of willingness, on the part of policy-makers, to implement harm reduction measures for IDU at the national level. The political environment surrounding illicit drug use has remained predominantly dictated by criminal justice approaches, and even though some movements toward incorporating harm reduction in the national HIV/AIDS response have been initiated, these public health initiatives have received little political and budgetary support. A few individual drop-in centers initially run by TDN under the GFATM project continue to operate in the post-GFATM Round 3 funding era, but do so under extreme financial duress and with little technical or financial support. Other initiatives started under that GFATM grant have been closed. In efforts to revitalize and ensure the continuation of community-led harm reduction initiatives, members of the TDN have since faced enormous challenges, including those related to collecting evidence of health care needs, accelerating capacity-building, and providing much needed harm reduction services to Thai IDU in a context of ongoing repressive enforcement-based drug policy.

Community-based participatory research (CBPR) is increasingly recognized as a valuable research approach that links academic research to goals of societal transformation (Israel, Schulz, Parker, & Becker, 1998; Travers, 1997; Wallerstein & Duran, 2003). While a large body of literature describes the principles and strengths of CBPR in various ways, a central tenet of CBPR is an emphasis on the participation of community representatives in all aspects of the research process to ensure that the research outcomes are relevant to the community, as well as to integrate the knowledge obtained with actions to improve the health and well-being of community members, and in turn empower the research participants and their communities (Hall, 1992; Harris, 2006; Israel et al., 1998; Kemmis & McTaggart, 2000; Minkler, 2005; Wallerstein & Duran, 2003).

While previous studies have described examples of CBPR applied to socially marginalized populations such as sex workers and transgenders (Clements-Nolle & Bachrach, 2003; Nyamathi et al., 2004; Shannon et al., 2007), there have been few descriptions of CBPR involving a community of people who use illicit drugs. Therefore, we sought to describe the Mitsampan Community Research Project in Bangkok, Thailand, one of the first CBPR involving people who use drugs in Thailand, by documenting how the project was conceptualized and implemented, as well as the outcomes of this particular CBPR project.

METHODS

An intrinsic case study methodology was used to describe the Mitsampan Community Research Project (Stake, 2005). Two members of the local community organization that collaborated with the CBPR project worked with three academic researchers in gathering data that were needed to describe the project. These two members of the local community organization were capable of communicating in both Thai and English and provided Thai–English translation to the academic researchers not fluent in Thai language. The data sources for the present study included participant observation conducted by the academic researchers and community members throughout the project period, including observation of project meetings, peer researcher trainings, data collection activities, as well as care and support initiatives and social gatherings that the local community organization carried out. Organizational records were also compiled to derive additional information about the participants and the project.

The data analysis was conducted across three study objectives: the description of conceptualization, implementation, and outcomes of the Mitsampan Community Research Project. Two members of the research team made several reviews of the collected data and developed an initial set of codes and key constructs. Subsequent reviews were used to assign data segments to categories. Following the merging of all data, the two community members validated draft summaries of the results.

RESULTS

Conceptualizing the Project

Mitsampan Harm Reduction Center (MSHRC) evolved from the Bangkok branch of TDN, which operated the center since 2004 with GFATM funding until that project’s closing in 2007. Located in an area in central Bangkok where many drug users reside, MSHRC provides a broad range of peer-led harm reduction programs including sterile syringe distribution, food and peer support, information (e.g., where to access health services), and education (e.g., safer injecting, overdose prevention and management; Kerr, Hayashi, et al., 2010). MSHRC continues the TDN tradition of actively addressing human rights abuses of drug users and advocating for their improved access to comprehensive prevention, care, and treatment.

Following the closure of the GFATM Round 3 grant in 2007, MSHRC faced enormous challenges due to a lack of funds. The majority of staff were discharged, most programming ceased, and the number of visits to the center by drug users plummeted. In the wake of these challenges, MSHRC requested that the community-based advocacy organization, TTAG (created by cofounders of TDN), take over its management and help secure funding to keep MSHRC open. TTAG and MSHRC representatives prioritized the need to increase the uptake of the center’s programs, as well as the need to collect local evidence for national policy advocacy that demonstrated the situation facing local IDU, and described their health needs and immediate health challenges. As a first step, in the fall of 2007, they consulted with researchers at the British Columbia Centre for Excellence in HIV/AIDS (BC CIE) in Vancouver, Canada, who had provided technical support with the development of their original GFATM grant application (Kerr et al., 2005). The first meeting was held
in January 2008, and MSHRC community members and the researchers at the BC CIE participated in a group discussion to identify the needs and goals of the group.

At the meeting, three key concerns were expressed by MSHRC community members: (1) the misrepresentation in media regarding the success of the drug war; (2) the continued lack and poor implementation of health care programs for drug users; and (3) the need for increased outreach and recruitment of drug users to MSHRC. MSHRC community members placed particular emphasis on the continued negative portrayal of drug users in Thailand and the continued lack of care and support for this population. One further concern was the emphasis of educational messages on the role of individual-level responsibility in preventing the spread of HIV without adequate identification of the broader contextual factors, namely, criminalization and severe punishment of drug users, which were known to shape HIV risk behavior among IDU.

Based on this assessment, the group discussed ways in which these issues could be addressed and decided to conduct a CBPR project. The data collection methods involved peer outreach into the IDU community and peer-conducted survey-based interviews, activities that were designed to increase attendance at MSHRC as well as to acquire information needed for advocacy efforts. The group set a target goal to recruit 200 participants. Researchers from Chulalongkorn University who had previously worked with MSHRC also agreed to join and support the project. The rather contradictory national policies pertaining to injection drug use in Thailand, specifically those that criminalize illicit drug use while admitting the needs for HIV surveillance and prevention for IDU, made room for research involving IDU to be conducted.

Implementing the Project

In June 2008, the Mitsampan Community Research Project was launched. Twelve active/former drug users (10 male, 1 female, and 1 “katoey” [transgender]) were democratically elected by MSHRC attendees to become peer researchers. These individuals were mostly polydrug users and have injected drugs at least once. The selection of the peer research team was undertaken by MSHRC attendees as a means of avoiding accusations of favoritism that could have arisen if the academic research partners had selected the team. These individuals helped design the overall study, and were trained in various aspects of research, including ethics, outreach, and survey administration. Two academic researchers from the BC CIE and a staff member from TTAG supervised and assisted the fieldwork of the peer research team. Specific duties that were assigned to these individuals included storage of surveys, handling of research honoraria, and the budget management. In addition, three Thai research assistants who had research experience with socially marginalized populations were recruited through Chulalongkorn University and other channels and provided logistic and communication support for fieldwork for academic researchers, including Thai–English translation.

The first 2 months were devoted to developing a detailed study protocol and survey instruments, completing peer researcher trainings, and building a trusting relationship between the academic and peer researchers. Many aspects of the project were managed by the community, which inevitably affected the timing and budget of the project. For example, the training speed could not be dictated by academic researchers, and the stipends paid to peer researchers and survey participants were negotiated with the community once the project was initiated. Although the project budget and time line were drawn up after the initial community consultation meeting, the academic researchers needed to have considerable flexibility to adapt to ongoing changes in the project plan.

A survey instrument was designed in consultation with the peer researchers in several phases. The first phase involved brainstorming about key issues in the community. The researchers then drafted a survey questionnaire to reflect these concerns, including gathering sociodemographic data and information about drug use patterns, injection behaviors, overdose history, sexual behaviors, health service utilization (including barriers to health care), and health conditions. Follow-up discussions involved fine-tuning the data collection instrument to ensure a proper scope of question topics and adjusting language discrepancies between English and Thai versions with the assistance of PS and KK, coauthors of the manuscript.

Participant recruitment strategies were carefully planned with consideration for the needs and assets of MSHRC. Three avenues were developed to recruit participants: MSHRC attendees, personal networks of the peer researchers, and outreach activities such as visiting locations—for example, methadone clinics—where IDU were known to congregate. Outreach activities targeted areas close to MSHRC to reach people who would likely return to MSHRC as service recipients after the participation in the project. All interviews were conducted at MSHRC. Transportation costs for the survey participants were fully covered, and free food was provided at MSHRC every day during the project period. Efforts to connect people to MSHRC through the project were expanded later, and various roles were created to make MSHRC as welcoming as possible to local IDU. These roles included greeting people at the entrance gate, touring them around the center, and offering food and drinks. This approach also provided opportunities for MSHRC members who lacked the capacity to assume roles that are more challenging—such as survey administration and outreach—to become involved in the CBPR project. At MSHRC, there were several members who could not meet the literacy level to understand the questionnaire, or who lived with physical disabilities, which made them difficult to conduct outreach.

The development of the CBPR partnership did not take a predetermined form but rather the academic researchers and the partners from TTAG constantly revisited issues of partnership, power, and collaboration as a part of the ongoing process. For example, issues related to the cash
payment to the study participants (i.e., honorarium) and peer researchers (i.e., stipend) were openly negotiated between the academic and peer researchers. The rationale, risks, and practical management of the cash payment were discussed, and the amount of payment that was deemed fair by the peer researchers was established. It was decided that peer researchers and study participants were given cash remuneration in a private space, not in an open space, so that people could not see who were getting paid. This process helped ensure the transparency of the project budget and avoid potential conflicts regarding the cash payment, a sensitive issue in a setting where the majority of community members were unemployed or engaged in temporary work.

Frequent discussion among the academic and peer researchers also facilitated practical wisdom and insights from the peer researchers, which helped ensure the smooth implementation of the project. For example, short working shifts were set so as to not overly tax peer researchers and to accommodate ongoing drug use behavior. Special consideration was given to the safety of the peer researchers and survey participants due to the repressive nature of drug policy in Thailand. All outreach work was conducted in pairs, and all staff carried identifying information (signed letters by the research institutions involved) with them at all times. These letters did not identify the peer researchers as drug users but as research staff. In fact, several outreach workers reported that they were stopped and questioned by police officers while working on the street. However, once they showed police the letters, they were released without any problems. In addition, efforts were made to preserve the anonymity of the survey participants throughout the data collection process. Through consultation with the peer researchers, it was decided that no identifying information would appear on questionnaires, and oral rather than written consent was obtained. Of note, there were no instances of harm associated with drug law enforcement reported over the course of the project.

The research team also experienced some challenges during the peer researcher training and data collection period. First, several factors affected the timing of the project. The academic researchers had to repeat the training several times (i.e., more than initially planned) because some peer researchers were unable to participate in an optimal fashion in the initial training sessions due to ongoing drug use, and others missed the sessions. In addition, since this was an internationally funded project, the team had to obtain ethics approvals from academic institutions in Canada and Thailand. As often happens in any research project involving vulnerable populations such as IDU, the ethics reviews took considerable time, creating a time lag between the completion of the training and the start of data collection. Thus, some parts of the training had to be repeated before data collection could begin. All these factors delayed the process, which in turn required that the academic researchers from Canada had to dedicate more time in Bangkok than was originally scheduled.

Further, varying competencies among the group of peer researchers posed a challenge to quality control related to data collection. The administration of the project surveys required excellent communication and interpersonal skills as well as a good memory to catch inconsistencies in reporting. Although extensive interviewer training was provided, some peer researchers needed substantial time to acquire these skills. This necessitated the academic researchers to extend close supervision and assistance to these peer researchers during data collection. In addition, although the research team established a policy requiring abstinence from substance use while on shifts, challenges arose when some peer researchers showed up for their interviewing shifts but were too intoxicated to undertake their duties. When intoxication was obvious, the peer researcher was asked to abide by the consequences preestablished by the team, such as being dismissed from the shift. Whenever such incidents occurred, the research team—including staff members of TTAG and the manager of MSHRC—held meetings to revisit the project objectives and discuss issues of professionalism. Significant time was committed to group discussion, scrutinizing surveys to ensure proper administration, and retraining peer researchers in this skill as necessary. Also, of note, the research team made efforts to build morale and trust and reinforce team-oriented approaches among the team members, such as giving out certificates for completing the peer researcher training and having various team-building activities.

At the end of data collection, the research team held a debriefing session to discuss the plan for data analysis and output. At this stage, the distinct skills of the academic and peer researchers were identified, and a division of labor was discussed. It was decided that the peer researchers would propose the priority of issues to be explored, whereas the academic researchers would contribute their scientific expertise to conduct the analyses. Copies of the questionnaires were translated into English and transported to the BC CIE in Vancouver to be entered into a secure password-protected database. Prior to the interpretation and dissemination of the research findings, the academic researchers returned to MSHRC and shared the preliminary findings with the peer researchers who verified the data, provided interpretations, recommendations, and suggested areas for further investigation. All the data were presented to the community before being released publicly out of respect for the academic-community partnership and a sense of accountability to the community. This process also served as a means of confirming that the interpretation of the data was in line with the local knowledge. In addition, MSHRC and TTAG were encouraged to request that the academic researchers perform data analyses and provide presentation materials whenever they had opportunities to advocate at local, national-, and international-level stakeholder meetings. The peer researchers continue to be involved in ongoing data analysis, interpretation of data, and dissemination of study findings.
Project Outcomes
The peer research team succeeded in accessing more than 250 IDU in Bangkok within 1 month. Of the 252 IDU respondents, 178 (71%) were new to MSHRC. Among these 178 new participants, 147 (82.6%) had not accessed MSHRC before simply because they did not know MSHRC existed. As shown in Figure 1, in the several months following the CBPR, a sustained increase in the cumulative number of the monthly MSHRC participants was observed, from 346 participants in July to 539 in August, 427 in September, 505 in October, 456 in November, and 454 in December 2008. Although once threatened with closure, MSHRC was able to stay open through the CBPR project and obtain external funding for its ongoing operation after the project.

At a debriefing session, the peer researchers acknowledged that their presentation and conflict resolution skills had improved over the course of group meetings held during the project. Furthermore, the peer researchers described improved communication skills and a deepened knowledge of the challenges faced by drug users in the community. The peer researchers also noted that they came to think seriously about the role of MSHRC for the community and strongly hoped to continue the outreach activities to maintain contact with the respondents.

At the time of the writing of this manuscript, seven manuscripts had been published in peer-reviewed journals, eight presentations were made at the 20th International Harm Reduction Association Conference that was held in Bangkok in April 2009, and three presentations were made at the 18th International AIDS Conference that was held in Vienna, Austria, in July 2010. The study findings have indicated a high prevalence of syringe borrowing resulting from difficulty accessing sterile syringes (Kerr, Fairbairn, et al., 2010), midazolam injection (Kerr, Kiaying-Angsule, et al., 2010), evidence planting by police (Fairbairn et al., 2009), harms associated with incarceration (Hayashi et al., 2009) and compulsory drug treatment (Kaplan et al., 2009), nonfatal overdose, and a lack of overdose prevention education (Milloy et al., 2010); the absence of deterrent effects of the enforcement-based drug policy on drug use patterns among Thai IDU (Werb et al., 2009); and the impact of MSHRC in providing essential harm reduction services to a subpopulation of Thai IDU, particularly vulnerable to poor health (Kerr, Hayashi, et al., 2010).

The CBPR approach also successfully led to fruitful knowledge translation activities. At the International Harm Reduction Association Conference, a pair of presenters that included an academic and peer researcher made each presentation. The peer presenters were democratically selected from the group of peer researchers on the basis of voluntary participation and having personal experience highly relevant to the topic. For example, one peer researcher recognized as an “overdose expert,” due to having had many overdoses, was unanimously selected by the group as a peer presenter on the topic of overdose. This approach allowed the peer researchers to participate in an international conference and made the presentations more effective because of the local knowledge and experience of the peer researchers, which in turn made a significant contribution to lively discussion in the sessions. Additional presentations derived from the project have been made in various settings in Thailand, Canada, and other countries.

In addition to academic journals and conferences, various knowledge dissemination routes and venues were sought in collaboration with the TTAG, whose expertise is policy advocacy. Plain-language policy briefs were produced in both English and Thai to make the
Our experience demonstrates how CBPR can be applied effectively to investigate health problems among IDU. Consistent with previous studies describing successes of CBPR with other socially marginalized and hidden populations such as sex workers (Benoit, Jansson, Millar, & Phillips, 2005) and transgendered individuals (Clements-Nolle & Bachrach, 2003), our experience indicates that the CBPR approach can be effective in quickly gathering information on hard-to-reach IDU populations and in connecting them to peer-run harm reduction programs, especially when an organized group of the affected community exists. In our project, it took 7 months from the first community consultation to the preparation for the fieldwork, 1 month for data collection, and 3 months for the initial data analyses, although further analyses and dissemination of data are still ongoing. In a context where repressive policies marginalize the population of focus, it is notable that new, scientifically sound information that adequately reflects the needs of local drug users has begun to emerge.

In addition, the success of our CBPR project underscores the importance of the active involvement of the community, especially in the initial phase of the project. A study from Canada pointed out that while CBPR has become popular in research involving people living with HIV/AIDS (PLWHA), levels of PLWHA’s participation in the research process were often low, and claimed that the low involvement of PLWHA in the early stages of research projects was especially problematic, as the research agendas likely did not reflect the issues that were relevant to PLWHA (Travers et al., 2008). Paradoxically, in our case, a bottom-up approach taken in the initial phase played a critical role in ensuring the relevance of the project results to the community, including future activities such as the operation of MSHRC and advocacy efforts. This approach also provided a means of providing information that countered the dominant cultural discourse that serves to stigmatize drug users and perpetuate the state-sponsored human rights violations against them.

We also experienced several challenges in undertaking this CBPR. Perhaps the most pertinent and unique challenge to CBPR involving active drug users was the issue related to cash payment. Many CBPR investigators have suggested that financial support for community participation would be needed to remove constraints on community involvement and resolve insider–outsider power imbalances (Minkler, 2004; Sullivan et al., 2003; Travers et al., 2008). While we agree with this reasoning, and believe that financial compensation certainly helped maintain a high commitment among peer researchers in our project, this can affect the power dynamics within the community. In particular, when academic researchers collaborate with an established group of active drug users who live in proximity to one another, share some living practices, and rely on one another, there potentially exist significant hazards with having a small group of peer researchers generate income through the CBPR project. Another challenge with cash payment is that it can temporarily create an economic dependency on the research project among community members. Therefore, it is extremely important that the rationales and safeguards related to cash payment are openly and continuously discussed and agreed among research partners. Our experiences suggest that CBPR is a
particularly suitable approach to handle this issue of cash payment, because its emphasis on community ownership of the project enables such open discussions to take place.

Our experience also indicates that the successful implementation of CBPR collaborating with a community of drug users builds on a fine balance between maintaining active participation of the community and accomplishing the project goals. First of all, many drug users live precarious lives, in the sense that they are extremely vulnerable to poor health, arrest, and compulsory drug treatment. Therefore, communities of drug users tend to be fluctuating, which may constitute significant barriers for the active community participation; as described in our case, nearly half of the peer researcher team was lost within a year. The vulnerability specific to this population requires that academic researchers exercise extra care, patience, and flexibility. In addition, reaching a balance between ideal and realistic forms of community participation can be especially tricky in cases of CBPR with active drug users. Although active participation of the community members is recognized as the hallmark of CBPR, the notion of “participation” in the literature on participatory research has often been conceived as a continuum, suggesting that the levels and nature of participation may change over time as the roles and relationships of each research partner are negotiated and renegotiated (Chung & Lounsbury, 2006; Cornwall & Jewkes, 1995). Israel et al. (2003) further argue that, given the distinct sets of skills and assets among the research partners, “different levels of involvement may be appropriate for different partners” (p. 63). It is also crucial to understand that “levels” refer to not only quantities but also qualities. This argument may be particularly salient to collaborative work with active drug users who have unique sets of expertise and capacity. However, it is important to note that the negotiation process itself needs active participation of the community and has to be premised on an authentic partnership among the research partners. In our project, although the academic researchers made every effort to remove barriers for community members to engage in the research process—including accommodating the peer researchers’ drug use—a line had to be drawn in terms of drug use during the work shifts to ensure the scientific rigor of the study. Without honest, ongoing communication among the research team, this boundary may have reproduced harmful power dynamics that community members experience in their daily lives.

Study Limitations
This case study has limitations. For example, we did not explore peer researchers’ experience in depth as a part of this particular study. Although some community members participated in developing this case description, other peer researchers may have had different experiences with the project. In addition, the case study may have been more relevant to other settings if it could have explored why the peer researchers were able to demonstrate high degrees of dedication to the project and how they perceived the personal benefits (or detriments) of participation in this academic-community partnership.

CONCLUSIONS

In conclusion, our case study shows that a CBPR approach can be effectively applied to health research involving the IDU community, and can serve to quickly reach and connect populations of IDU to essential harm reduction services, especially when an organized group of the affected community exists. Our experience also demonstrates that CBPR can promote community empowerment while obtaining valuable epidemiological data for advocacy purposes. However, ethical and practical challenges pertaining to collaborative work with active drug users need to be addressed through honest, ongoing communication among the research partners. Future research should be conducted in order to indentify ways of optimizing CBPR with IDU.

Declaration of Interest

The authors declare that they have no competing interests.

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GLOSSARY

Community-based participatory research (CBPR): CBPR is not a method but an orientation to research that values active collaboration of the potential beneficiaries throughout the research process and seeks to link academic research with actions to promote societal transformation. CBPR is increasingly recognized as a valuable research approach to addressing health inequities in the field of public health.

Community empowerment: The process through which communities or groups of people who share common interests, concerns, identities, or norms gain power to control their lives. The process often involves community action aiming at societal and political change.

REFERENCES


