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Community-based participatory research (CBPR) approach to study children's health in China: Experiences and reflections

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Abstract

Background—Community-based participatory research principles have been successfully applied to public health research in U.S. settings. While there is a long history of collaboration between government and communities in China, to date, community-based participatory research has not been used in children's environmental health studies.

Method—This article describes how community-based participatory research principles were applied by an international research group to the China Jintan Child Cohort Study, a longitudinal study of malnutrition and lead exposure on cognitive and neurobehavioral development. Challenges emerged and lessons learned from implementing the study were discussed and recommendations were presented.

Conclusion—We conclude that the community-based participatory research model can be applied in conducting and promoting environmental health research in China and researchers should be prepared for special challenges and cultural constraints in the implementation of the research in regards to human subject regulations, information dissemination, and culture.

Keywords

Community-based participatory research; CBPR; Lead; Children; China; Environmental health

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1. Introduction

Israel et al. (1998) defined community-based participatory research (CBPR) as a research focusing on “social, structural, and physical environmental inequities through active involvement of community members, organizational representatives, and researchers in all aspects of the research process.” Through the contributions of all partners, including the U.S. research team, participating local parents and students, school teachers, regional government officials, and hospital staff, the aim of CBPR is to combine knowledge of interventions and policy changes to achieve better health status of involved communities. The rationale, principles, and benefits of CBPR have been extensively discussed (Israel et al., 2003, 2005). CBPR principles have been successfully applied to the development and the conduct of an increasing number of public health research projects (Bogart and Uyeda, 2009; Brown et al., 2005; Din-Dzietham et al., 2004; Krieger et al., 2002; Lengerich et al., 2007; Metzler et al., 2003; Parker et al., 2003; Paschal et al., 2008; Pazoki et al., 2007; Savage et al., 2006). The CBPR model can be seen as research “with” the community rather than research “on” the community (Ali et al., 2008). In addition, the model can serve as a bridge between participating parents and students, government representatives, and researchers. Benefits of CBPR have been well recognized (Israel et al., 1998). CBPR ensures that the research topic comes from, or reflects, a major concern of the local community and brings together all partners with different expertise. By involving local knowledge of local partners, CBPR enhances the validity, quality, relevance, and usefulness of research data. CBPR may also help overcome the understandable distrust of research on the part of communities that have historically been the “subjects” of such research.

The CBPR model has been utilized for nearly 25 years and has served as an important tool to advance environmental health sciences in the United States (Arcury et al., 2001; Brody et al., 2005; Brugge and Cole, 2003; Cook, 2008; Cummins et al., 2010; Downs et al., 2010; Horn et al., 2008; Israel et al., 2001; Kegler et al., 1998; Latowsky, 2003; Levy et al., 2006; Minkler et al., 2006; Parker et al., 2003; Petersen et al., 2006; Schell et al., 2005; Schulz et al., 2001; Wier et al., 2009). More recently, the CBPR model proved a useful approach in children’s environmental health and disease prevention research (Israel et al., 2005; Kegler et al., 2000; Moodie et al., 2010; Parker et al., 2008; Petersen et al., 2007; Schetzina et al., 2009). Building on previous experiences, the National Institute of Environmental Health Sciences (NIEHS) recommended that every CBPR program should contain six main principles: (1) promoting active collaboration and community-based participation at every stage of research, (2) fostering co-learning, (3) ensuring projects are community-driven, (4) disseminating results in terms useful to all collaborators, (5) ensuring research and intervention strategies are culturally appropriate, and (6) defining the community as a unit of identity (O’Fallon and Dearry, 2002).

While CBPR has been increasingly recognized in the US, this model has been rarely used in public health research in China. China’s rapid economic growth within the past decades has led to serious environmental issues such as outdoor pollution, water quality, and pesticide residuals in food products (Liu et al., 2010a,b,c). The children’s health in China is threatened by both traditional and emerging environmental pollutants (Ye et al., 2007). Though the governmental structure in China is different than in the US, the long history of

collaborations between the government, industry, and communities in China suggests that CBPR may be an effective way to foster environmental awareness within communities and encourage different groups to take action on environmental issues (Ali et al., 2008). To date, there have been no published accounts of full-scale CBPR projects in China. Nevertheless, some studies have reported community involvement in the process of translating US measurement instruments into versions culturally appropriate for the community (Chang et al., 2006).

In this paper, we describe the process of developing and conducting The China Jintan Child Cohort Study (Liu et al., 2010a,b,c) using CPBR principles. We wanted to use this study as a case to present the feasibility and challenges of applying CPBR principles in China. We believe our experiences may benefit investigators, especially those who are not familiar with China and other populations sharing similar culture and research environment. We then highlight challenges and lessons we experienced and our recommendations for other investigators.

1.1. The China Jintan Child Cohort Study (CJCCS)

The study site of CJCCS, the city of Jintan, has been of concern to local health workers and investigators due to environmental pollution problems, such as smelter, cement, chemical, and plastics factories, related to rapid development of small industrial facilities. The majority of factory jobs are in manufactory industries such as smelter, cement, and electronic cables with lead exposures. Wang and colleagues (Wang et al., 2009) found that the weekly lead intake per body weight in children living in this area was higher than that of adults, and 30% of the children had a weekly intake that was greater than the provisional tolerable weekly intake defined by the Joint FAO/WHO Expert Committee On Food Additives.

The CJCCS project was conceived in 2002 and initiated in 2004. Guided by the our conceptual framework for understanding the relationship between early health risk factors and children's behavioral outcomes (Liu, 2011), the aim of this study is to examine the long term impacts of early exposure to environmental toxins (mainly lead) and malnutrition on the development of children's and adolescents' neurocognitive and neurobehavioral outcomes, in which interactions between environment and nutrition will also be investigated. The study involved a close collaboration between American and Chinese scientists and the Jintan community and was designed to include many years of follow up. Between autumn 2004 and spring 2005, all children (age 3–5 years old) attending the four pre-schools in the area were invited to participate in our study. Baseline data on blood lead and micronutrients was assessed for 1656 children. The first follow-up from 2005 to 2007 included IQ tests, behavioral outcomes, as well as psychosocial, health and demographic information for 1385 children in the cohort. Children from the original cohort are now enrolled in several Jintan elementary schools and the second follow-up for 2009–2010 at the elementary schools included measures of cognitive ability, academic records, school performance, health data (e.g. sleep pattern and nutrition status), and behavioral outcomes. Table 1 shows main measures planned at each stage of follow-up.

2. The CJCCS partnership

The partnership includes health workers from 3 governmental public health and medical agencies (Jintan Department of Health, Jintan Hospital, and Jintan Maternal and Child Health Center), parents and teachers from 4 community schools, and academic researchers from 4 universities (University of Pennsylvania, China Southeastern University Medical School, Shanghai Jiaotong University Research Center for Children's Environmental Health, and Psychology Department of Hong Kong University). A steering committee consisting of representatives from these groups was formed to guide the project's decision making and research process.

The Jintan Maternal Child Health Center (JMCHC) and the Jintan Hospital are two technically related but financially independent divisions of the Jintan Health Department and are the public health and primary care providers to local communities and schools. The JMCHC provides public health and preventive medical care services to women (premarital check-ups, medical check-up prior to obtaining a marriage certificate, diagnoses of sexually transmitted diseases, etc.) and children (overseeing the growth and development of pre-school children) in Jintan. The Center offers healthcare to pre-school children in the city and provides preventative visits to more than 50,000 women and children every year. As part of its duties, the Center performs annual physical checkups for pre-school children and generates reports for the Jintan City government and parents. The long-term history of collaboration between health department/ hospital and community/school has built a strong mutual trust and a working network which are key bases for the community partnership of this project.

Researcher-community partnership was formed based on mutual interests. The principal investigator (PI) from the University of Pennsylvania is originally from and educated in this area and has maintained personal and academic connections with local health professionals and academic institutions. Partnership between the community and the University of Pennsylvania was formally established after local public health leaders extended an invitation to the PI to work together. The academic research team was then expanded to include researchers with expertise in relevant aspects of the study. The Shanghai Key Laboratory for Children's Environment Health in Shanghai Jiaotong University is the only laboratory in China that focuses on children's environmental health. The laboratory prepared the protocol for blood lead specimen collection and provided the team with research assistants (pediatric nurses). In addition to blood lead levels, we were also interested in whether lead exposure and nutrient deficiency together negatively affect the behavior of children. We initiated collaboration with the Nutrition Department at China Southeastern University in Nanjing, Jiangsu Province. Both Jiaotong University and Southeastern University have extensive community research experiences in local settings. In the interest of researching child behavior, we also established a collaboration with the Psychology Department at Hong Kong University, working with investigators holding extensive knowledge and experience in the psychometric properties of the Achenbach Child Behavior Checklist (CBCL) (Achenbach, 1991).

3. Quality control

While our CBPR study shares many principles with other studies, we have a particular challenge which stems from the international nature of our collaboration. While the PI spent 3–4 months during the most rigorous data-collecting periods, she was not physically on site throughout the entire process. Therefore we were presented with challenges in ensuring the quality control and assurance of our study design, staff training, data collection, and sample handling.

3.1. Training and preparations

In the two years prior to the start of the project, the PI and local contacts began preparations in screening and hiring bachelor-trained pediatric nurses, orienting them on the research plan, and training them on the data collection procedure, similar to the international, community-based study in the Dominican Republic by Foster et al. (2010). Particular attention was given to educate the nurses to avoid potential bias, piloting data collection and data entry. The training sessions were updated at a yearly basis to ensure the staff's skills and knowledge were refreshed and up-to-date with the progress of the project.

During this process, regular phone conference calls (2–3 times a week) between the PI and local monitors at JMCHC and Jintan Hospital were held to discuss and resolve challenges and obstacles. As suggested by Zhao et al. (2009), quality and productivity of the research were ensured by local monitors who regularly exchanged ideas with and provided feedback to the PI via phone and Skype conferences.

3.2. Data collection

Quality control during blood data collection is especially important because specimen sample can be easily contaminated if not handled properly. We made efforts to ensure the quality of data collection by sending all of the nurse staff members to Shanghai Jiaotong University, where the blood samples were analyzed, to be trained for adhering to strict research protocol to avoid lead contamination. We also made efforts to ensure the quality of administering other questionnaires. For IQ test administration, the two pediatric nurses received an intensive three-week training course by the clinical psychologist, an expert on IQ testing, who also supervised the entire IQ testing process.

To ensure data collection quality, we administered a pilot IQ test to determine the reliability and also implemented test-retest reliability method and repeated measurement for all of the surveys and questionnaires we administered.

Since our overall goal is to test the direct, indirect, and interactive effects of environmental toxicant exposure on children's behavioral development in a longitudinal setting which involves different waves of testing, we are using multiple statistical methodologies to test our hypotheses, including multivariate analysis using structural equation model fitting and hierarchical multiple regression.

3.3. Data safety monitoring plan

To ensure that the disclosure and protection confidential of information standards were in compliance with US federal guidelines, all information collected in this study was kept in the strictest confidence. Codes rather than names were used on all information sheets and computer records used in the research study. Once all paper records had been entered into the computer, the original paper records were destroyed after three years of completion of the study.

4. Study process guided by CBPR principles

4.1. Community-driven research questions

One of key principles recognized by NIEHS is ensuring projects are community-driven, indicating all CBPR research questions should be guided by the concerns of community and should be built on community needs (O’Fallon and Dearry, 2002). While working with schools and communities, local health workers had received inquiries regarding their concerns about the health impact of nutrition and lead exposure. Previous monitoring has shown high levels of lead in children’s hair samples. Lacking sufficient research and risk analysis ability, the Center sought external expertise from the PI to develop a study to understand, from an epidemiologic perspective, whether lead exposure in Jintan impacts children’s cognition and behavior and what would be the optimal strategy to promote lead prevention and educational programs. Specifically, the center was interested in knowing: (1) what are the major sources of lead exposure? (2) do exposures at the current level adversely impact children’s neurobehavioral and cognitional development? and (3) what are the appropriate approaches to reduce lead exposure and minimize health impact?

After defining the research questions and purposes, the PI began to work with the local health staff and communities to develop the study design and protocol. A focus group meeting was held to discuss study process. This initiative was funded by the Department of Science and Technology of Chang Zhou City (Jintan city is part of Chang Zhou City) together with the Wacker Foundation from the US.

4.2. Selection of community partners

To identify and select appropriate communities and community partners, a working group with members from the governmental health department, JMCHC, Jintan Hospital, and local school board was established. We define a community as a school within one of three types of geographic and socioeconomic areas (central city, suburban, rural). Pre-school children ages 3–5 years old are our study population. The key reason for the separate grouping of the three communities was that each area has specific profiles and concerns related to malnutrition and environmental pollution. Four pre-schools, Jianshe (central city), Huacheng (suburban), Xuebu and Huashan (rural), were selected. Our community partners include the local health department, hospital, the schools, and steering committee of parent representatives. The partners have been involved in each stage of the study as described below.

4.3. Role of community partners in conduct of the study

In addition to guide the development of previously discussed research questions, community partners actively participated in developing research protocol, field works, and finding dissemination.

4.3.1. Tailoring questionnaire and instruments—A pilot study was conducted among a small group of children with representatives from the steering committee to help evaluate the appropriateness of the interview questionnaire, including questions about basic demographics, family characteristics, eating behavior, and nutrition. The questionnaire was then revised based on suggestions from this pilot. For example, from the pilot study, we learned that half of the children were raised by both grandparents and parents. Therefore, our questionnaire also included grandparents' social-demographic data. Another example is when we collected nutrition data, the steering committee suggested that it would be more reliable to ask parents if their child "ate breakfast regularly", instead of "the frequency of eating breakfast per week." The research included several assessments related to behavioral and psychosocial dynamics factors. Chinese versions of the Wechsler Pre-school and Primary Scale of Intelligence-Revised (WPPSI-R) and Child Behavior Checklist (CBCL) Caregiver-Teacher Report Form were used to assess children's cognitive ability and behavioral outcomes. Although Chinese versions of these instruments have been validated and applied in China, additional validation was undertaken to ensure that these instruments fit local setting. We held several focus groups with members of the community to discuss the meaning of the words in the Chinese versions to ensure the questions were culturally appropriate and retained the original meaning of the instrument. These focus groups were composed of pre-school principals and teachers, elementary school teachers, parents of the cohort subjects, school nurses, local researchers, and pediatricians. For example, the Chinese version of the CBCL was originally translated by a professor from the Chinese University of Hong Kong, and because Hong Kong culture/language differs slightly from mainland China's, the focus group believed that there was a need to modify the wording of the Hong Kong Chinese version of the CBCL. With the community's input, we modified the wording of some of the items in the original translated versions of the CBCL to ensure cultural relevance for a Mandarin-speaking population. These revised Chinese translations of the CBCL have become the standard Mandarin-speaking Chinese Version CBCL acknowledged by Dr. Achenbach, the author of the CBCL (Liu et al., 2010a). Similar procedures have been applied to other translational instruments, such as parental-bonding instruments (Liu et al., 2010b).

4.3.2. Implementation of field work—The researchers proposed to acquire nutritional information and responses to various healthcare assessment questionnaires throughout the year. However, the community members, including school teachers and parents, wanted to collect the information just once during the annual parents' meeting at the school. This meeting is widely prevalent in Chinese schools and is one that every teacher and parent is expected to attend. The researchers received the suggestion to collect information during the meeting from the focus group parents and eventually agreed that the suggested method would produce equally good results.

4.3.3. Hiring local research staff—Research assistants were employees of our local partners. These nurses have been providing community health services to local residents, including school children. Most of the nurses grew up locally and have deep understanding of local settings. A teacher from each study site was employed as a school project coordinator, providing expertise and knowledge about the parents and children and serving as a bridge between the research team and study participants.

Local staff played a key role in our recruitment and follow-up success. We recruited 1656 three to five year-old children from three pre-school cohorts representing city, suburb, and rural communities in 2004. As indicated in Table 2, both initial recruitment rate (97%) and consequent specimen collection rate (98%) were high. Indeed, these recruitment rates were higher than other studies conducted in China (Li et al., 2009; Liu et al., 2008; Wang et al., 2007). Participating rates were also very high during the first two follow-ups. Among the 1656 children recruited at baseline, 1620 (98%) provided blood samples. We obtained valid blood samples (after analysis) from 1576 children, who were the sole subjects of our study henceforth. Out of these 1576 students, 1385 (88%) participated in the first follow-up data collection including the measurement of IQ, behavior, health, as well as demographic and psychosocial data. The study is still ongoing, but we anticipate a strong retention rate. We will also assess the children's social competence and peer relationships in a future follow-up.

4.3.4. Dissemination of study findings—In 2008, we gave the first Jintan Research progress report to the city council and community to report our preliminary analysis. In this report, we described main preliminary findings (see Table 3) and the implications of these findings for communities, children and their families. Eight percent of children had blood lead levels greater than 10 µg/dl, the level at which lead toxicity becomes a health concern (Gilbert and Weiss, 2006). We found that several sociodemographic factors, including gender (boys), age, parental education, parent occupations, father's smoking at home, living in a rural area or crowded neighborhood, and eating breakfast fewer than five days per week were positively associated with blood lead levels. These findings suggest some corrective actions, such as increasing breakfast frequency, may help to reduce these levels, and relevant measures were recommended to communities.

The dissemination of preliminary findings has promoted further actions guided by community partners. For example, in response to the finding regarding higher mean blood lead levels in children from the rural area (Xuebu), a new project was initiated to study the association between soil lead and blood lead levels. We hypothesized dust and soil lead in Xuebu is linked to the children's elevated blood lead levels. The next step of the research proposal was generated during our focus group meeting to further investigate the exact sources of lead.

4.3.5. Researcher-community interaction—Researcher-community interaction is promoted through multiple communication channels to maintain sustainable partnership. University researchers worked with JMCHC and the hospital to hold training workshops on lead exposure prevention and standard height/weight measurement for school nurses. This training opportunity promoted collaborative ties with school nurses who consequently

played a significant role in coordinating data collection with classroom teachers. Weekly telephone conferences are held to address any questions related to the project. We also hold weekly teleconferences or meetings with the JMCHC, which leads local research activities and community communications.

Working with university students (from both the US and from China Southeastern University), public health workers (nurses and pediatricians), and school teachers/ school nurses, we developed several public workshops on lead exposure prevention and nutrition. We have set up poster presentations in the local pre-school and elementary schools, whose topics included “The facts of harmful effects of lead on children,” “Where lead exposure comes from in daily life,” “The consequences of lead exposure in children,” and “Prevention tips.” We have also developed a nutritional education program which includes topics such as “New Chinese Food Pyramid” and “Healthy food choices.” We generally held these presentations at the end of the school day to reach a larger audience and build more relationships. During community presentations, we were able to communicate with the children, school teachers, school nurses, and parents and speak with some of them individually, which enables us to increase their knowledge and skills regarding lead exposure and prevention and nutrition.

Meanwhile, we held health education fairs to further strengthen our communication with the community. The fairs were open to all children and parents in Jintan, not just those involved in the research project, and featured individual medical consultations with pediatricians, nutritionists, psychologists, and nurses from the research team. We offered free measurements of blood pressure and body mass index as well as simple physical exams performed by physicians and nurses in Jintan Hospital. In addition, the fairs included workshops for the parents and children to learn proper nutritional practices and measures to prevent lead exposure. The health fair during the summer of 2008 was featured in the headline news by Jintan city media, which more broadly educated residents beyond the immediate vicinity of the schools and hospital.

5. Challenges and lessons

5.1. Challenges

Israel et al. (2005) have discussed major challenges in children’s environmental health research using CBPR principles in the US. In addition to encountering the challenges discussed by Israel, we have also faced other challenges that resulted from the cross-cultural differences in informed consent, subject compensation, research supervision, release of behavioral assessment results, and the view of governmental involvement.

5.1.1. Ethical review and informed consent—Ethical issues surrounding human subjects research were the first challenge we encountered at the first stage of developing this study. The local research team, without any training or experience in human study ethics, believed that testing the lead levels in children was part of the JMCHC’s public health work, thus no consent was needed from the parents. Traditionally in China, participation in human research falls under the responsibility of the organization collecting the data. For instance, if the organization were a school and a teacher asks something of the students, the students

would fulfill the request. Therefore, the collection of a specific informed consent agreement and compensation have not been viewed as compulsory in the past. The majority (76%) of participants in a Chinese epidemiologic study considered the project as part of routine healthcare measures and almost all participants would agree to participate in a similar study in the future (Lynöe et al., 2004). Ethical review committees were established in most major universities, hospital, and research institutes since the adoption of the Declaration of Helsinki recently adopted in China (Ministry of Health, 2007). However, the effective implementation remains a concern due to limited detailed instructions, the lack of training for investigators, and the low education level of many patients (Hennig, 2006). Meanwhile, such a review process has rarely been formalized at the local public health level. Recognizing the importance of following international ethical standards, Jintan Hospital formalized an Ethics Review Committee. The NIH Human Subjects Training Course was translated into Chinese and offered to the local team. Each local team member completed the Collaborative Institutional Training Initiative (CITI)'s Online Training module designed to educate the member on research ethics and received a certificate upon completing the program. The local team consequently accepted the idea of informed consent. The study process was reviewed and approved by IRBs in both countries. The project was explained to students, school teachers, and parents. Parents were required to sign a consent form. 6% of parents refused to participate. Of those approving their children's participation, 2% refused blood drawn. Consequently, consent agreement was reviewed and accepted by each participating subject, i.e. the students and the parents.

5.1.2. Financial compensation of participating families—The IRB in the US institution believed that subjects should be financially compensated for their involvement, and the PI proposed offering a small gift to each child/ family for their participation. The JMCHC, however, initially believed that it was the children's and parents' duty to participate in public health research and did not want to compensate the participants for their involvement. A special meeting was held between the PI and leaders of the local team to discuss disadvantages and advantages of compensating subjects. We laid out the general practice in the US related to human subject research, including compensation, which was aimed to reimburse subjects for expenses, reduce financial sacrifice on the part of the subjects, and compensate them for their time and effort. A consensus was eventually made to provide a small gift to the participants.

5.1.3. Appropriate research methodology—There was disagreement on the data collection methods for the project. Local research staff wished to follow their traditional ways which could be described as a practical public health approach. However, university researchers aimed to use sound research methodology to conduct the research. For example, traditionally, the annual check-up conducted by the JMCHC measures lead level and micronutrient status via collection of hair samples. We recognized that despite the fact that hair lead analysis is the simplest, most convenient, and cheapest method of sample collection, the validity of this measurement is questionable due to the problems associated with exogenous contamination. We had several discussions with project staff regarding the reasons for using blood samples. The negotiations with local team on this issue led to an agreement to use blood sample testing.

5.1.4. Finding dissemination—There was some disagreement about what data should be presented to the children and parents. While both the academic researchers and community partners agreed that test results from physical exams, blood lead levels, and micronutrient levels would be given to the parents of the children, there was disagreement regarding IQ and neurodevelopmental test results. The parents and the school teachers expected to have results of the IQ and behavioral assessment scores sent to them immediately after the assessment, an expectation which was also shared by the local health department as such practices are quite prevalent in the research communities in China. In the US, however, it is not common practice to return test results such as IQ scores and other behavioral assessments unless the results concern the children's immediate physical wellbeing and safety (Brody et al., 2007; Shalowitz and Miller, 2005). In fact, the US IRB disapproved the plan for parents to receive the IQ and behavioral scores. The main concern was that IQ and personal traits are inheritable and therefore the release of such results might cause unnecessary distress for the parents of children who have lower IQ scores. Recognizing such cultural differences, we held several focus group meetings to discuss the issue and finally reached an agreement (in compliance with the US IRB) that the IQ test results and behavior scores would not be released to the parents and teachers.

By respectfully discussing the different topics and cooperating to achieve a suitable agreement, we were able to overcome disagreement in ethical concerns, methodology, compensation method, and results release. In addition, through various meetings, presentations, and focus groups, we were able to actively involve the community, including the parents, teachers, hospital staff, and local government officials, in the research to develop an environment for co-learning and foster a trusting relationship. We were able to maintain this connection through periodic meetings and conferences to make sure no problems were arising. Overall, through the principles of CBPR, we were able to establish a deeper connection with the community than we would have been able to do otherwise.

5.2. Lessons and facilitating factors

Various facilitating factors described by Israel et al. (1998) were keys to our success. First, the study was in the local community and government's best interest and also fits the PI's research background and interest. The local health department (JMCHC/Jintan Hospital) played the leading role in defining research questions, based on their perceived priorities and community health need. The Chinese people have a strong relationship with government-run health centers. As a community organizer, the department and its divisions (JMCHC/ Jintan Hospital) served as a bridge between the research team and the community (i.e. schools and families). Second, the study protocol was jointly developed by academic researchers and community partners. During this process, community partners guided the revision of interview questionnaire and measurement instruments, as well as offering advice on the field work process. Third, effective community communications and interactions have built strong trust. Workshops, focus group discussion, and presentation actively promoted communications between academic researchers and the local communities. In addition to regular meetings with local health staff, trainings covering human subject research ethics, the administration of study instruments, and the collection of biological samples strengthened local health worker's research capacity and the community's understanding of

lead exposure and toxicity. For the first time, the local staff was trained to measure IQ and child behavior. The local team has expressed interest in expanding the training and using the tools in their future research and practice. Lastly, the PI's Chinese background has made it easier to communicate with local staff and the community.

5.3. Building research capacity

Though already discussed in detail in other parts of the manuscript, it is important to point out that our implementation of CBPR contributes to the overall research capacity for both the academic and local community in elements similar to themes described by the North American Primary Care Research Group Committee (2002). These themes include: the ability to build linkages, adequate infrastructure, the ability to enhance training, reputable researches, ability to publish, the right questions asked in the right setting, and funding. For example, our study demonstrates the ability to build linkages by the fact that our collaboration has built a research network between academics and community health providers beyond the initial research project. Our study laid the foundation for current and future students at China Southeastern University School of Public Health to become actively involved in community health research in local Jintan areas through collaboration with Jintan local hospitals. Additionally, our study demonstrates the ability to publish through the 7 manuscript currently published (e.g. Liu et al., 2011), obtained 3 US government funded grants, and 3 Chinese local-city grants.

6. Recommendations

Building on our lessons and experiences in using CBPR in this project, we present our recommendations to international investigators.

- Respecting the government's leading role in developing research question and coordinating the study is of the utmost importance.
- Establishing and maintaining trust with local leaders is critical and having an individual who speaks Chinese and knows the cultural differences between China and western countries is essential.
- Essential training on human subject ethics and research methods is necessary to build local research capacity and conduct high quality research.
- Flexibility in tailoring research protocols to fit the local settings without reducing quality is a key.
- Providing medical consultations, education programs, and health results will help to establish trust between the research team and communities.
- The uniqueness of nurses' roles in community health can put them in special positions to be able to actively lead CBPR research in order to improve the health status of involved communities.

7. Conclusion

CBPR is a systematic approach which equitably involves the community and academic partners in the research process and balances research and action for the benefit of all

involved. CBPR is being increasingly recognized as a promising approach in many research settings, and this study can serve as a beginning model for researchers, doctors, and nurses conducting CBPR studies in China as well as other developing countries to improve children's environmental health around the world. This particular project arose because of a mutual research interest: understanding the effect of lead exposure on the health of children. While we faced a number of challenges that resulted from the differences in culture and policy, we have proved that CBPR can be a useful tool to advance children's health research in China. We hope the lessons we learned and experienced will be helpful for nurses and other healthcare professionals who wish to conduct CBPR in international settings.

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Abbreviations

CBPR	community-based participatory research
CJCCS	China Jintan Child Cohort Study
NIEHS	National Institute of Environmental Health Sciences
JMCHC	Jintan Maternal Child Health Center
PI	principal investigator
IRB	Institutional Review Board
CBCL	Child Behavior Checklist

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What is already known about the topic?

- The community-based participatory research (CBPR) model has been utilized for nearly 25 years and has served as an important tool to advance health sciences in the United States by involving community members, organizational representative, and researchers together in all aspects of the research process.
- Through the contributions of all partners, including the research team, participating local subjects, and regional administration officials, the aim of CBPR is to combine knowledge of interventions and policy changes to achieve better health status of involved communities.
- However, while CBPR has been increasingly recognized in the US, this model has been rarely used internationally outside of the US, especially developing countries, including China.

What this paper adds

- This study is the first publication on CBPR used in China, which can serve as a beginning model in China as well as other developing countries for future community-based research and promoting CBPR for nurses and other healthcare professional who are intimately involved in the process of conducting CBPR research.
- The China Jintan Child Cohort Study, an environmental health study in China, exemplifies potential applications of CBPR to investigators who are interested in using this method in China.
- For applications of CBPR studies in China, but potentially also for other international developing countries, we recommend respecting the government's role, establishing and maintaining trust with local leaders, remaining flexible in tailoring research protocols to fit the local setting, and investing in essential training on human subject ethics and research methods.

Table 1^a Main measures in the China Jintan Child Cohort Study (CJCCS).

Measures/instruments	Status	Locations	Status	Child age
Enrollments (informed consent)	Baseline	Preschool	General consent completed	3–5
Blood sample collection	Baseline	Preschool	Completed: in 2004–2005	3–5
Blood Assay: Lead (graphite furnace atomic absorption spectrophotometry)	Baseline	Shanghai Lead Prevention Center	Completed in 2005	4–5
Blood Assay: Micronutrients	Baseline	Preschool	Completed in 2005	4–5
IQ testing: age 5 (WPPSI-R)	1st follow-up	Preschool	Completed in 2005–2007	5–6
Growth data: height/weight	1st follow-up	Preschool	Completed in 2005–2007	4, 5, 6
Health data	1st follow-up	Preschool	Completed in 2005–2007	5–6
Retrospective birth complication				
Infant developmental data				
Breast feeding history				
2nd hand smoking exposure				
Nutrition survey				
Sleep behavior				
Demographic /Psychosocial Data	1st follow-up	Preschool	Completed in 2005–2007	5–6
Parental education, occupation, Marital status				
Size of house				
Neighborhood environment				
Child Rearing Disagreement				
Parental Report				
Child Behavior Checklist (CBCL, TRF)	1st follow-up	Preschool	Completed in 2005–2007	5–6
Academic records	2nd follow-up	Elementary school	On-going	7–12 Grade 1–6
Health data	2nd follow-up	Elementary school	On-going	10–12
Nutrition survey				Grade 4–6
Social Competency and Peer Relationship	2nd follow-up	Elementary school	On-going	10–12 Grade 4–6
Child Behavior Checklist: (CBCL/TRF/YSR)	2nd follow-up	Elementary school	On-going	10–12 Grade 4–6

General consent has been obtained from the subjects during the first phase of blood drawing. RAs are Pediatric Nurses (RN, BS) who received training in IQ testing and data collection.

^aThis table is adapted from Table 1 in Cohort Profile Paper, Liu et al. (2010a,b,c).

Table 2

Recruitment and follow-up of children in the China Jintan Child Cohort Study.

Process	<u>Recruitment (2004 baseline)</u>		<u>Wave 1 follow-up (2005–2007)</u>	
	Number	%	Number	%
All children in 4 kindergartens	1757			
Children(parents) agreed to participate	1656	1656/1757 94%	–	–
Children provided blood samples	1620	1620/1656 98%	–	–
Valid blood sample	1576	1576/1620 97%		
Parents completed psychosocial questionnaire			1385	1385/1576 88%
Children completed IQ tests	–	–	1331	1331/1576 84%
Mother's rating on Children's behavior	–	–	1296	1296/1576 82%
Teacher's rating on Children's behavior	–	–	1313	1313/1576 83%

Table 3

Summary of major findings disseminated to community partners.

Indicators		Findings
Blood lead level (BLL)	Median (range)	6.2 (1.8, 32.0) µg/dL
	Elevated BLL(±10 µg/dL)	7.8%
	Predictors of elevated BLLs	Being girls, older age, having sibling(s), living in a crowded neighborhood, living in rural area, parent's smoking at home, and eating breakfast less than five days per week.
Nutrition	Calcium deficiency	38.9%
	Iron deficiency	24.2%
	Zinc deficiency	38.3%
	Copper deficiency	0.6%
	Magnesium deficiency	0.3%
Baseline IQ	Performance IQ	104.0 ± 15.0
	Verbal IQ	103.9 ± 14.8
	Full scale IQ	104.2 ± 14.4
Behavior	CBCL total	33.6 ± 20.9
	TRF	19.8 ± 17.0
		Preliminary analysis shows that even at sub-clinical levels, blood lead is linked to increased externalizing behavior in pre-school children.