Dissemination of Results in Community-Based Participatory Research

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Context: Community-based participatory research (CBPR) has been promoted as an approach to understanding complex health problems not amenable to research conducted solely by outside investigators. Although broad dissemination of research results is a key element of the CBPR approach, existing dissemination efforts have not been assessed.

Evidence Acquisition: In this systematic review, researchers evaluated studies utilizing the CBPR approach to characterize dissemination of research results beyond scientific publication. Specifically, the focus was on dissemination to community participants and the general public. The literature search encompassed articles published between January 1, 2005, and December 31, 2009. Corresponding authors were also invited to complete a web-based survey. Data were collected and analyzed between July 1, 2008, and March 8, 2010.

Evidence Synthesis: In all, 101 articles met inclusion criteria. All articles were assessed for the quality of community involvement in research. Scores ranged from 1.4 to 3.0 (on a 3-point scale), with a mean of 2.3. The 21 articles in which an intervention was evaluated were scored for the rigor of research methods. Scores ranged from 2.0 to 2.9 (on a 3-point scale), with a mean of 2.4. Dissemination beyond scientific publication was reported in 48% of publications with varying levels of detail. However, among survey respondents, 98% reported dissemination of results to community participants and 84% reported dissemination to the general public.

Conclusions: Among research meeting strict criteria for inclusion as CBPR, dissemination beyond scientific publication is largely occurring. However, myriad challenges to timely and widespread dissemination remain, and current dissemination to community participants and the general public is variable.


Introduction

Dissemination of research results beyond scientific publication, specifically, to study participants and the general public, is an ethical responsibility of researchers1–4 and a fundamental aspect of translational research.5 In academic spheres, however, dissemination is generally defined more narrowly as publication in peer-reviewed scientific journals. The audience for such journals generally does not include study partici-
pants or the general public—the people whom research ultimately aims to affect. This limited definition of dissemination may be one reason for the time lag of 10–25 years between research discoveries and their eventual impact on the health of populations.6

One potential avenue for addressing this time lag may lie in community-based participatory research (CBPR), an approach to research of complex health problems not amenable to research conducted solely by investigators outside the community of interest.7 CBPR requires cooperation between academic and community partners at each phase of research, including broad-based dissemination, with the goal of using knowledge to encourage action toward social change and improved health outcomes.8–11

Substantial prescriptive literature exists4,12–15 detailing potential methods of dissemination in the CBPR ap-
proach. However, to date there has been no systematic evaluation of dissemination beyond scientific publication, particularly to community participants and the general public, nor have the range of current dissemination efforts and specific challenges to broad dissemination been described. The present review is the first to systematically characterize dissemination in the CBPR approach, beyond scientific publication and encompassing all activities in the spirit of knowledge transfer.4

Methods

The current review focused on health-related publications utilizing the CBPR approach, with a specific interest in dissemination beyond scientific publication addressed within the published article. Corresponding authors of included articles were also invited to complete a survey to provide additional information on dissemination. Data were collected and analyzed between October 1, 2008, and March 8, 2010.

Literature Search

The literature search was conducted using OVID’s MEDLINE, PsycINFO, and CINAHL (Cumulative Index for Nursing and Allied Health Literature) for the period January 1, 2005, to December 31, 2009, using the Key words “community-based participatory research,” “participatory action research,” “community partnership,” “community academic partnership,” “community-based organization,” and “community participatory methods.” An additional search was performed using the combined subject headings “consumer participation” and “research,” and “community-institutional relations” and “research.” Search terms were determined after reviewing existing CBPR literature and compiling associated key words and subject headings.

Study Selection

The initial search yielded 5430 articles: 1780 from OVID’s MEDLINE, 794 from PsycINFO, and 2856 from CINAHL.

Exclusion Criteria

Duplicates, research unrelated to health, studies based outside the U.S., reviews, dissertations, meeting abstracts, and non-English publications were excluded. Articles that described a research process but did not identify a research question and report results were also excluded.

Studies based outside the U.S. were excluded because the goal was to examine the dissemination of CBPR results within the framework of the U.S. healthcare system. Although lessons learned in other nations may also be applicable to the U.S., differences in history, culture, and political norms may differentially affect the approach to dissemination and partnerships with communities.

One author reviewed titles and abstracts of all articles and applied exclusion criteria. A second author reviewed titles and abstracts of articles excluded in this process to verify fidelity to the criteria. All disagreements were resolved by consensus, resulting in a total of 377 articles.

Inclusion Criteria

After reviewing existing definitions of CBPR,6,16–18 two primary criteria and three secondary criteria were established (Appendix A, AppB). Articles included in analysis had to fulfill both primary criteria for CBPR and at least one of the secondary criteria for CBPR.

All four authors independently reviewed an initial group of ten articles with 100% inter-rater reliability. Remaining articles were divided and independently reviewed for inclusion. The team met regularly to discuss any articles that individual reviewers had difficulty classifying. One hundred articles met inclusion criteria.

Bibliographies of the 100 included articles were reviewed for any articles published between January 1, 2005, and December 31, 2009, not returned in the initial literature search. This yielded an additional 1 article meeting all criteria for inclusion, bringing the total of included articles to 101 (Appendix B, available online at www.ajpm-online.net). The search strategy is further detailed in Figure 1.

Data extraction was conducted by using a standardized template developed by the research team to capture all relevant data. An initial group of ten articles were extracted together to ensure consistent application of the template. An additional ten articles were then independently extracted with 100% inter-rater reliability. The remainder of the articles were then independently extracted, with regular meetings to discuss any areas of uncertainty. Disagreements were resolved through consensus.

Figure 1. Flow diagram of search strategy

www.ajpm-online.net
Quality Scoring

All included articles were scored for the quality of community participation in research. In addition, the quality of research methodology was assessed for all articles in which an intervention was evaluated. Criteria for scoring were established by group consensus based on the scoring mechanism used in an earlier study that assessed the CBPR approach to research (Appendices C and D, available online at www.ajpm-online.net). An initial group of ten articles were independently scored, with 95% inter-rater reliability. The 5% of cases in which there was disagreement were thoroughly reviewed and additional criteria for scoring were established. The remaining articles were then independently scored in groups of 20 articles. After each group of 20 articles was completed, scores were reviewed. Differences were resolved by consensus. Final scores were then reviewed.

Survey

A web-based survey was developed to provide a forum for corresponding authors to discuss any dissemination that may not have been described in publication.

Survey Administration

Corresponding authors of all included articles were e-mailed an invitation containing a link to the web-based survey, using information provided in publication. When this information was not provided or was not accurate, a search was performed using the Google search engine. If the corresponding author’s contact information was not available by searching Google, a telephone call was made to the corresponding author’s last known place of work to obtain contact information. Valid contact information was obtained for 91 corresponding authors.

Two weeks after the initial invitation was sent, a reminder e-mail was sent to all nonresponders.

Data Collection and Analysis

An 11-question survey (Appendix E, available online at www.ajpm-online.net) was administered via a web-based survey tool (SurveyMonkey.com). Six questions were multiple-choice, and four of those included an open-ended response option. The remaining five questions had only open-ended responses.

Open-ended responses were reviewed using established methods of content analysis, a method used to analyze the content of recorded communication using systematic, verifiable techniques to categorize and classify large amounts of textual data. The constant comparative method was used to review all open-ended responses independently to identify emergent themes. This was an iterative process in which verbatim quotations were classified into essential concepts using labels developed iteratively to reflect the data. Concepts were synthesized into unifying and recurrent themes. Finally, both authors reviewed all open-ended responses to compare the content to the themes, resulting in agreement on a single set of unifying and recurrent themes with illustrative quotations.

Results

Systematic Review

The comprehensive search strategy identified 101 unique articles for review. Based on information available within the published article, articles were scored for the quality of community involvement in the research process. In addition, the 21 articles that evaluated an intervention were scored for research quality. Appendix B (available online at www.ajpm-online.net) provides summary information for articles selected for inclusion.

Information available within published articles indicated that results had been disseminated to either community participants or the general public in 48% of articles (n=48). However, the scope of discussion surrounding dissemination efforts was variable, ranging from a single line stating that dissemination had occurred, to an entire section devoted to describing the dissemination process.

The federal government was the largest funding source for included studies, providing partial or complete funding for 61% (n=62) of included studies. Other notable sources of funding included foundations (28%, n=27); academic institutions (17%, n=17); and other government funding such as state, local, and tribal governments (9%, n=9). A broad range of study types were included, from process evaluations to needs assessments and intervention trials. Community partners were also varied and included community-based organizations, faith-based organizations, and business leaders.

Quality Scoring

All articles selected for inclusion in this systematic review were scored for the quality of community participation in research, using information available within the published article. Scores were based on domains such as the nature of community involvement in research and the extent to which community-based participatory research elements were present (Appendix D, available online at www.ajpm-online.net). Articles were scored on a 3-point scale, with higher scores reflecting higher quality. Scores ranged from 1.4 to 3.0, with a mean of 2.3 and a SD of 0.3.

Forty-two percent (n=42) of articles described community involvement in the dissemination of research findings. This participation ranged from community participants deciding how, when, and where to disseminate study findings to community participants presenting study findings at various meetings, both academic and nonacademic, and community participants being involved with manuscript writing.

The two most frequently reported elements of community participation were (1) the study’s assessment of socioeconomic determinants of health through the design of...
of the study or intervention (95%, n=96) and (2) the use or intended use of study findings to address health concerns through application to a health-related intervention or policy change (95%, n=96). The aspect of community participation least often reported in published articles was community involvement in financial responsibility for grant funds, with 15% of studies (n=15) describing this element of community involvement.

In addition, the 21 articles that evaluated an intervention were scored for research quality. These scores assessed the rigor of the study design with randomized, experimental studies receiving higher scores. Scores ranged from 2.0 to 2.9 on a 3-point scale, with a mean of 2.4 and a SD of 0.2. Seven of the 21 articles describing an intervention reported data from pilot or feasibility studies. Scoring this element of community involvement.

Survey

Sixty-five of the 91 authors with valid contact information completed the online survey (71% response rate). Ninety-eight percent of survey respondents (n=63) reported that results had been disseminated to community participants whereas 84% (n=55) reported that results had been disseminated to the general public. Twenty-six percent (n=17) of respondents reported that they had disseminated results to community participants at each step in the research process, spanning time points both pre- and post-publication, whereas 23% (n=15) of respondents reported that they had disseminated results to the general public at each step in the research process. In contrast, 45% of respondents (n=29) reported that results had been disseminated to community participants at only one time point in the research process, whereas 65% (n=42) reported that results had been disseminated at only one time point to the general public.

The majority, 97% (n=63) of respondents, noted that the original research plan had included dissemination to community participants. Sixty-six percent (n=43) reported that dissemination to the general public had been part of the original research plan. Eleven percent of respondents (n=7) reported that requirements of funding organizations had influenced the timing of dissemination to community participants. Nine percent of respondents (n=6) reported that such requirements had influenced the timing of dissemination to the general public. Examples of such requirements by funding organizations are as follows: the inclusion of plans for dissemination beyond scientific publication in grant proposals, funds held in reserve specifically for the purposes of dissemination, or the specification of dissemination beyond scientific publication as a deliverable in a contract.

Respondents used multiple strategies for disseminating results. The most common format for dissemination to community participants was organizing a meeting (77% of respondents, n=50). The most common format for dissemination to the general public was media coverage (51% of respondents, n=33). The least common format for dissemination to community participants was a phone call (15%, n=10), and the least common format for dissemination to the general public was postings such as posters and flyers (17%, n=11). Respondents also reported relying on one-to-one or word-of-mouth dissemination, in which dissemination relied on existing relationships of individuals involved in the project with others in the community.

Content Analysis

Open-ended survey responses were analyzed using established methods of content analysis to further understand how survey respondents characterized dissemination in the framework of studies using the CBPR approach. This generated five recurrent and unifying themes: (1) Dissemination is intrinsically valuable, both as a core principle of CBPR and for its role in developing and maintaining relationships between academic and community partners; (2) the needs and goals of various stakeholders in the collaboration can affect dissemination; (3) literacy and cultural differences are important considerations in dissemination efforts; (4) time and resource constraints affect dissemination; and (5) dissemination can play a vital role in spurring and sustaining change.

Dissemination is intrinsically valuable, both as a core principle of CBPR, and for its role in developing bolster and maintaining relationships between academic and community partners. Respondents cited the principles of CBPR and commitment to community–academic partnership as touchstones during all phases of research, particularly dissemination. This respondent reported: “We have a CBPR partnership . . . built on mutual trust, sharing of knowledge, and respect. Therefore, we are working with our partners to return all results of interest, and to explain the long term nature of [our] research.”

Similarly, this respondent’s dedication to the partnership and the principles of CBPR reinforced the commitment to dissemination. “We have tried to disseminate to community participants every time we have a chance . . . even if it was not originally planned because a key component of PAR/CBPR . . . is to maintain good communication between academic and community actors, and to generate opportunities for co-participation to really occur.”
This commitment to the partnership also manifested in a sense of responsibility to the participants, as detailed by this respondent: “We always disseminate as many of our findings as possible. I would consider it unethical to withhold this information from the community participants.”

The needs and goals of various stakeholders in the collaboration can affect dissemination. Respondents noted the potential conflict between the funding and publication timelines of academic partners and the iterative, action-oriented nature of research using the CBPR approach. “Part of the tension in a CBPR project is to provide timely communication, generally during the funding life cycle of a project, which does not always mesh with publication timelines. We did extensive outreach and communication during the project . . . but did not make similarly intensive efforts after publication, because by that point the project funding had concluded and the infrastructure was no longer in place.”

This respondent noted that dissemination beyond scientific publication did not contribute to professional advancement and therefore, was not a priority. “Working in an academic setting, the emphasis (sadly) is on procuring additional grant funding, not supporting past projects. Consequently, much of the work I do is not disseminated as widely as I would like.”

This respondent feared that dissemination might jeopardize publication opportunities. “We disseminated to partners throughout the process but we did not disseminate to partners’ funders and potentially influential policy makers as early as we would have liked because of the risk of getting rejected from publication because of early dissemination.”

Finally, community and academic partners often engaged in separate, decentralized dissemination efforts, as noted by this respondent: “Many partners were in charge of their own dissemination including reaching the general public or community participants. Dissemination has been difficult to follow given the nature of the project.”

Literacy and cultural differences are important considerations in dissemination efforts. Respondents noted that cultural and linguistic differences among academic partners, community partners, and community participants were important to account for when planning for dissemination. This respondent noted several challenges: “Translating research findings into simple language that is understandable by lay community members, limited funding for dissemination, additional work that is required to do a culturally and literacy appropriate dissemination (which is not acknowledged by the academic system).”

This respondent noted that translating research findings for a lay audience was a vital piece of dissemination, but one that lacked dedicated funding: “We have plans to write a lay piece but have not done it . . . the piece [is] potentially very important for moving the [partner’s] agenda forward but the analysis . . . is hard to understand so we need to figure out a way to make the information more accessible.”

Time and resource constraints affect dissemination. Respondents specifically acknowledged the time and resource constraints inherent to research endeavors partnering with underserved communities and using CBPR. This respondent noted: “People are very busy with many priorities, particularly among those with lower incomes—working two jobs, caring for children. [It’s] more challenging to get to meetings. We provided food and child care and door prizes to increase participation when we could.”

This respondent noted the difficulty of dissemination in the context of the long timelines often required for projects using the CBPR approach: “Staff turnover and/or change in agency leadership at the community agency [over time] were a common barrier to effective dissemination.”

Finally, this respondent curtailed dissemination efforts out of concern that broad dissemination might generate further interest, which might require support and resources that were unavailable: “I have limited my dissemination activities because I do not have the resources to assist more organizations who may want to replicate the participatory model.”

Dissemination can play a vital role in spurring and sustaining change. Respondents reported that thoughtfully planned dissemination could encourage social change in the community while promoting sustainability. This respondent noted: “Dissemination is all about feedback, using data from the project to generate feedback reports that give meaningful information to community participants. Feedback reports foster new interest and activities among community partners that develop new capacities for addressing many kinds of community health issues. It’s about exchanging knowledge and developing relationships that lead to new, more impactful projects and interventions.”

Dissemination could also contribute to obtaining new sources of funding, as reported by this respondent: “[Dissemination] was necessary to help the communities leverage additional resources.” Finally, this respondent described how dissemination efforts were sustained beyond the original timeline because of the commitment fostered by the CBPR partnership: “Even though funding by the original agency has expired, dissemination has continued and will continue. These efforts are led by the original...
researchers and their partners, agricultural organizations, other various stakeholders [and] the federal agency who originally initiated the funding.”

Discussion

Despite the importance of dissemination as a fundamental component of research using the CBPR approach, the results of the present study suggest that substantial challenges to dissemination remain. Even among studies meeting strict criteria for CBPR, there is great variability in the application of CBPR principles, particularly with regards to dissemination. The current study also highlights several innovative ways in which community and academic partners collaborated around dissemination of research results. One study used a local movie theater screen to disseminate aggregate results to community members. Another employed cultural symbols instead of bar graphs or pie charts to convey research results to community participants. Such efforts are particularly important in research using the CBPR approach to ensure that efforts to generate action and community change are not viewed as judgments on the community by academic researchers. Although academic–community partnerships for research represent a bold step forward from traditional research approaches, there is still room for improvement in establishing authentic community–academic partnerships. Some communities have established community research centers, owned and led by communities themselves and funded independently of academic partners. Such efforts move further toward equal collaboration of community and academic partners while addressing issues of the sustainability of health interventions introduced by research partnerships.

These findings should be considered within the context of the study limitations. The search strategy identified only articles published in peer-reviewed scientific journals. Given the focus of the CBPR approach on community action and social change rather than manuscripts and publication, it is likely that studies not identified by this algorithm may have been effectively disseminating research results. However, given the global trend toward translational research and community involvement in research, it is important to establish a baseline for understanding dissemination in the CBPR approach as perceived by academic partners. Second, quality scores were assessed based only on information available within publication. Therefore, it is possible that low scores for some articles may reflect omission of information within publication rather than a lack of community involvement in research and/or a lack of rigor in research methodology.

The current study also had a number of strengths. The literature search was comprehensive, encompassing a range of disciplines. Inclusion and exclusion criteria were developed using established CBPR literature. The scoring system used for evaluating the quality of community participation in the research as well as the rigor of the study methodology was based on an existing scoring methodology. The survey was developed and piloted with assistance from members of a CBPR listserver and the research team has diverse professional experiences and an interest in both research utilizing the CBPR approach and dissemination of research results.

The present study also raises several areas of focus for future work. First, challenges and barriers to dissemination from the perspective of community partners should be understood, as they likely differ from the limitations of academic partners. Second, although research using CBPR is assumed to result in increased dissemination to participants over traditional research modalities, direct comparisons have not been conducted and may be worthwhile. In addition, the effect of various incentives to disseminate research results beyond scientific publication deserves further exploration, particularly the role of funding organizations, peer-reviewed journals, and academic institutions in encouraging and perhaps even requiring such dissemination. Finally, future work should assess whether dissemination is disproportionately limited for vulnerable populations, who might gain the most from a CBPR approach.

Conclusion

Among research meeting strict criteria for inclusion as community-based participatory research, dissemination beyond scientific publication is largely occurring. However, challenges to timely and widespread dissemination remain. The present work serves as a baseline for evaluation of current efforts, while guiding future dissemination of research results. Without systematic emphasis on the importance of dissemination beyond scientific publication, it is less likely to be incorporated into research proposals and funding requests or to be mentioned in publication—the currency of academic researchers. This, in turn, perpetuates the cycle in which research results cannot immediately contribute to meaningful changes in clinical practice, building community capacity and improving health outcomes.

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Appendix
Supplementary data

Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.amepre.2010.05.021.