REVIEW PAPER

Youth as Partners, Participants or Passive Recipients: A Review of Children and Adolescents in Community-Based Participatory Research (CBPR)

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Abstract Community-based participatory research (CBPR) is an orientation to research that places value on equitable collaborations between community members and academic partners, reflecting shared decision making throughout the research process. Although CBPR has become increasingly popular for research with adults, youth are less likely to be included as partners. In our review of the literature, we identified 399 articles described by author or MeSH keyword as CBPR related to youth. We analyzed each study to determine youth engagement. Not including misclassified articles, 27 % of percent of studies were community-placed but lacked a community partnership and/or participatory component. Only 56 (15 %) partnered with youth in some phase of the research process. Although youth were most commonly involved in identifying research questions/priorities and in designing/conducting research, most youth-partnered projects included children or adolescents in several phases of the research process. We outline content, methodology, phases of youth partnership, and age of participating youth in each CBPR with youth project, provide exemplars of CBPR with youth, and discuss the state of the youth-partnered research literature.

Keywords Community-based participatory research ·
Children · Youth · Adolescents

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A Review of Community-Based Participatory Research (CBPR) with Youth

Community-based Participatory Research (CBPR) is an orientation to research that values the role of community members and academicians as equitable partners, each contributing unique strengths to the research process (Israel et al. 1998). In contrast to more traditional research, in which "experts" from academic institutions develop hypotheses based on the literature and then enter communities to recruit subjects, projects using a CBPR orientation rely on the input and contribution not only from academic researchers but also from community members at each step of the research process, from defining the research topic to disseminating the results (Minkler and Wallerstein 2008). Although specific research methods used in CBPR vary widely, CBPR projects are distinguished by the value placed on cooperative efforts that engage community members and researchers equally in decision-making and in the relevance of the research for communities (Israel et al. 2005).

CBPR has become more popular over the past 10 years, particularly in research focusing on health and underserved communities. The benefits of CBPR are well matched to these arenas. As researchers study health and social phenomena and recognize that a multitude of complex factors influence individual behavior, the role of the "outside expert" has become increasingly obsolete. By partnering with individuals who would previously have been the "subjects" of research, CBPR studies are more likely to focus on practical problems of importance to the community and to uncover contextual factors contributing to these real world problems. The knowledge generated from CBPR is culturally relevant and connected to people's lived experiences and thus is more readily translated into action

than knowledge that is generated from academic theory or from outsider perspectives. Perhaps even more important than the direct benefit CBPR studies have on communities is the potential for indirect benefits resulting from the CPBR process. By partnering with community members, particularly marginalized individuals often without power and status, CBPR provides an outlet to express needs and concerns and to build community capacity to address them (Wallerstein and Duran 2008). As such, CBPR is characterized as "an empowering process through which participants can increase control over their lives" (Minkler and Wallerstein 2008, p. 9).

Considering the benefits of CBPR, children and adolescents are ideal candidates for community-academic partnerships. Although the academic literature quite often focuses on issues affecting youth, it is relatively unusual for youth to be included in the research process (Langhout and Thomas 2010). Without the voice of youth, research can miss the contextual input necessary to represent the unique youth experience. However unlikely it may be that adult investigator-driven research accurately captures the youth perspective, it is even less likely that the results of that research will be disseminated to and accepted by youth. By partnering with youth to identify content area, research questions, data collection methods, and appropriate dissemination efforts, researchers significantly increase the chances that research findings will be applicable to children and adolescents living in the real world.

Academic investigators might be reluctant to partner with youth, particularly younger children, based on the impression that a child's cognitive skills are not developed enough to understand empirical concepts. Classic Piagetan theory postulates that children do not develop the ability to engage in abstract reasoning until the formal operational stage typically reached at 11 or 12 years old (Piaget 1973); however, recent research suggests that the appearance of scientific reasoning skills are highly reliant on contextual factors and can be observed much earlier (Kloos and Sloutsky 2005). As a result, recent science education research has focused less on what children can do at a particular age but rather on "what children can do under what conditions" (Zimmerman 2005). In terms of CBPR, this cognitive science research suggests that even younger youth can have the cognitive capacity to understand basic research concepts when the material is presented in a contextually appropriate way.

Although CBPR with children and adolescents is less common relative to adult-driven work, the practice of partnering with youth to conduct research on youth-related issues is becoming more prevalent in the literature. In fact, the American Journal of Community Psychology devoted a special issue to "Participatory Action Research in Collaboration with Children," a set of fourteen articles describing studies in which children served as research collaborators and/or agents for social change (Langhout and Thomas 2010). Although incredibly diverse in method and scope, the common factor in youth-partnered research is the shift from the typical power dynamic inherent in the adult/child relationship to include youth as active participants in one or more phases of the research process. Investigators conducting youth-partnered research have described the benefits as well as the challenges, including a significant time investment, extra effort, and loss of control (Flicker 2008).

Although the prevalence of CBPR with youth studies has increased, it can be difficult to determine the degree to which studies described as community-based participatory research are actually partnering with youth community members. Journal page limitations that truncate descriptions of partnerships and a lack of standardization in the peer-reviewed literature in the use and meaning of CBPR terms make it difficult to make conclusions about the prevalence of CBPR practices (Viswanathan et al. 2004). When reading through the literature, it is clear that the CBPR label is often attached to work that does not rely on shared decision making between community and academic partners and sometimes functions without any community input at all. The distinction between research that is community-partnered and that which simply takes place outside the academic laboratory (community-placed) is important because working with community members reflects CBPR core values while conducting traditional investigator-led research in communities does not (Minkler and Wallerstein 2008). In order to understand the state of the art with regard to youth-partnered CBPR, we must analyze the existing literature to get an accurate picture of youth involvement in research.

In the current article, we have conducted a review of the literature on CBPR with youth to identify the frequency with which youth are included as partners and the role of youth in the research process. Specifically, we asked two research questions. First, to what degree are studies described as CBPR with youth actually using a community-based participatory research orientation with youth partners? Second, among those studies using a CBPR orientation with youth partners, what is the role of youth in the research process?

Methods

Search Strategy

To identify references for CBPR and youth, PubMed, Scopus, and Web of Science databases were searched using MeSH heading, keyword, and topic searches. Search terms included 'community-based participatory research', and

'child', 'youth', or 'adolescent'. Each article identified using these search terms was manually inspected for relevance.

Selection Criteria

Inclusion criteria included English-language articles published from 1985 to January 31, 2012 that referenced CBPR and youth. Only published articles in refereed journals were included. Because we were interested in articles willing to claim the terminology of CBPR, we excluded those articles only alluding to participatory practices and not specifically described as CBPR.

Data Extraction

From each manuscript identified in the literature search, we extracted author, journal, and year of publication. We read through each article to identify content area, research method, and youth involvement in the research process. The subset of manuscripts that described studies that partnered with youth to conduct research was further analyzed to determine the degree to which youth were involved in the project. Two of the authors separately coded this subset of manuscripts based on phase of youth involvement; disparate results were taken to the third author to determine final coding.

Results

Research Question #1: To What Degree Do Studies Described as Community-Based Participatory Research with Youth Actually Use a Community-Based Participatory Research Orientation with Youth Partners?

A total of 399 articles using "community-based participatory research" and "youth", "child", or "adolescent" as keywords or MeSH terms were identified. The projects described in these 399 articles varied considerably in the degree to which they incorporated youth as partners in research. Fourteen manuscripts appeared to be misclassified, as they were unrelated to CBPR altogether. Ten of these 14 misclassified articles were from one journal issue. We classified the remaining 385 articles into categories based on the degree to which youth were involved in the research (see Fig. 1).

Twenty-seven percent (n = 104) of the manuscripts described research that was *community-placed*, or conducted in a community setting. Projects in this category were described either by the authors or by MeSH indexers as CBPR but did not include a participatory component of
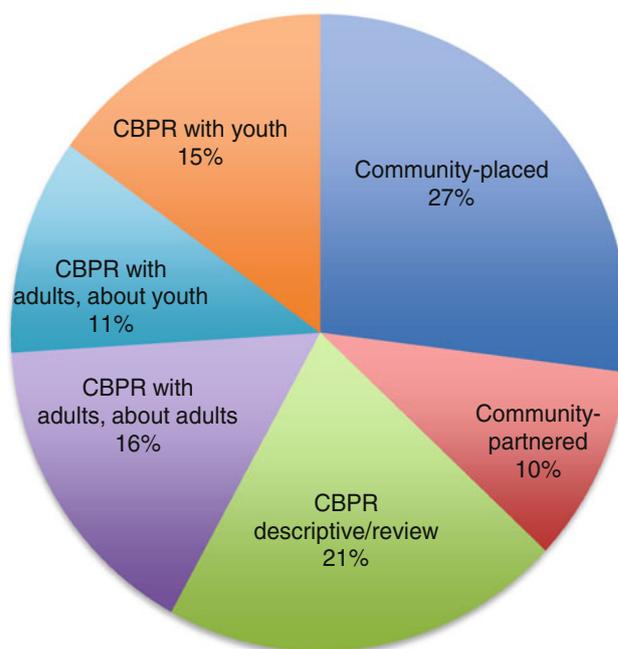
Fig. 1 Distribution of 385 manuscripts described as "CBPR with youth" by type of project

any kind. Instead, these studies conducted traditional research that took place in a community setting. Of the 104 manuscripts in the "community-placed" category, authors of 32 % (n = 33) of studies used "community-based participatory research" either in the abstract or as an author keyword (or both). Although the authors of the remaining 68 % of "community-placed" studies did not specifically use "CBPR" when describing their work, these articles still appeared in our search because a MeSH or keyword indexer assigned the keyword "CBPR" to the study.

Ten percent (n = 40) of manuscripts described *community-partnered* projects, or research partnerships formed with community members or community organizations. *Community-partnered* studies were not classified as CBPR because community members did not participate as contributing partners in the research process. Instead, academic and community partners worked together to facilitate research that would benefit the community organization. For example, researchers conducted body index assessments with students in a rural school district and research results informed policy and curriculum changes (Filbert et al. 2009). Fourteen of the 40 articles focused on research in which a community partnership was formed with a community-based organization NOT related to youth issues directly (e.g., REACH-Meharry community-campus partnership to address disparities in cardiovascular disease and diabetes; Fort and McClellan 2006) or with a specific population of adult community members (e.g., Somali immigrant women, Pavlish et al. 2010).

Twenty-six of the 40 *community-partnered* articles focused on research studies in which a community partnership was formed with a community-based organization directly related to youth issues (e.g., YMCA and children's body image; Davis et al. 2009) or with a specific population of youth (e.g., Mohawk children 6–11 years old; Paradis et al. 2005).

Twenty-one percent (n = 81) of the reviewed articles were CBPR-specific *descriptive or review* articles. These manuscripts described lessons learned from the CBPR research process or from a specific CBPR project. Of these 81 works, 49 were not focused on youth but instead on general aspects of doing CBPR (e.g., CBPR in environmental health science; O'Fallon and Dearry 2002) or on projects in the community directed more at adults (e.g., rural sex workers in China; Weeks et al. 2010). Twenty-seven of the 81 articles were process-level descriptions of youth-focused CBPR projects (e.g., Positive Youth Project; Flicker 2008).

Finally, 41 % (n = 159) of the reviewed manuscripts described projects that utilized a research process consistent with the CBPR orientation (Israel et al. 2005). We characterized 60 of these articles as *CBPR with adults, about adults* because they described CBPR projects with adult partners that focused on content specific to adult populations. For example, Garcia and colleagues collaborated directly with both rural and urban Latino adults to develop a survey that assessed mental health status, beliefs, and knowledge of resources (Garcia et al. 2008). We classified 43 articles as *CBPR with adults, about youth* because they described projects that partnered with adults on projects focused on issues related to youth. For example, Correa et al. (2010) partnered with two Houston neighborhoods to develop various community interventions to address childhood obesity. The remaining 56 of the 159 articles, or 15 % of the total 385 articles reviewed, were classified as *CBPR with Youth* because they focused on CBPR projects in which community partners were children and/or adolescents.

Research Question #2: Among Those Studies Using a Community-Based Participatory Research Orientation with Youth Partners, at What Level are Youth Involved in the Research?

To investigate how youth were involved in the 56 projects that actually partnered with youth in the research process, we created non-mutually exclusive categories, Phase 1–Phase 5, to describe youth involvement in the different stages of research. These five phases are based on the work of Barbara Israel and colleagues, who organized their seminal book *Methods in CBPR for Health* around five phases of research, which they label "(1) partnership formation and maintenance, (2) community assessment and diagnosis, (3) definition of the issue, (4) documentation and evaluation of the partnership process, and (5) feedback, interpretation, dissemination, and application of results" (Israel et al. 2005, p. 13). In the 2nd edition of the book, the authors include a figure that visually depicts this process (Israel et al. in press). To understand the role of youth in CBPR, we analyzed whether or not youth were engaged in each of five phases. In studies meeting criteria for *Phase 1*, youth actively gave input into the research through a Youth Advisory Board or other formal group/council mechanism. In *Phase 2*, youth were involved in identifying priorities, goals, and research questions through a needs assessment or similar process. In *Phase 3*, youth were involved in designing and conducting the research. In *Phase 4*, youth participated in data analysis, summarizing the data, and/or interpreting and understanding research findings. In *Phase 5*, youth participated in disseminating and translating research findings.

The degree to which youth were involved in CBPR projects varied considerably (see Table 1). Youth were most commonly involved in several phases of research, with 21 % involving youth in two phases, 23 % in three phases, 29 % in four phases, and 18 % involving youth in all five phases. Only 9 % of studies involved youth in only one phase of the research. In terms of classification into individual phases, youth most often participated in Phase 2, the identification of needs, priorities, and goals of research (77 %) and in Phase 3, designing or conducting the research (84 %). Fifty-nine percent of studies utilized a youth Advisory Board (Phase 1). Youth were least likely to be involved in Phase 4, data analysis (54 % of studies) and Phase 5, disseminating and translating research findings (52 % of studies).

The 56 studies that partnered with youth on CBPR projects focused on a wide range of content areas (see Table 1). Health issues were the most common area of focus with five studies focusing on general health issues, seven on obesity and/or diabetes, six on sexual health, three each on physical activity and substance use, and two each on environmental health and mental health. Another large portion of studies (11) focused on youth wellness. Studies in the "wellness" area addressed general wellness perspectives from the perspective of a particular population (e.g., Latina girls; Streng et al. 2004), the influence of a specific factor on general wellness (impact of mobility on African children; Porter et al. 2010), or a set of several specific outcomes (e.g., lead poisoning, teen mothers, and child maltreatment; Clark 2010). Seven studies focused on engaging youth in changing the school environment and 4 focused on issues of safety and/or violence. Finally, 6 studies were about projects with youth engagement as both the process and the outcome variable of interest.

Table 1 Content, methods, phases, and ages of youth involvement in CBPR studies with youth

Reference	Broad content area	Design/methods	Phases of youth involvement					Age of youth
			1	2	3	4	5	
Adler et al. (2008)	School environment	Mapping solutions, community outreach	✓	✓	✓	✓	✓	High-school students
Bardwell et al. (2009)	Obesity/diabetes	Community-based clinical research	✓	✓	✓	✓		11th graders
Bogart et al. (2011)	Obesity/diabetes	School-based intervention	✓	✓	✓		✓	7th graders
Branch and Chester (2009)	Obesity/diabetes	Community-based clinical research	✓	✓	✓			9th–12th graders
Chen et al. (2010)	Wellness	Participatory program evaluation	✓	✓	✓	✓	✓	10–15 years
Christiansen (2010)	Mental health	Digital storytelling, group intervention	✓	✓	✓	✓	✓	12–18 years
Chung et al. (2005)	Sexual health	Researcher-led focus groups	✓	✓				Adolescents
Clark (2010)	Wellness	Multi-method "Mosaic" approach	✓		✓	✓		~3–6 years
Demnis et al. (2009)	General health	Participatory photo mapping		✓	✓	✓	✓	10–18 years
Diamond et al. (2009)	Substance use	Train the trainer intervention			✓	✓	✓	14–25 years
Downs et al. (2009)	Environmental health	Community needs assessment	✓		✓	✓	✓	Teens
Duckett et al. (2010)	School environment	Interviews, journals, experiential walks	✓	✓	✓	✓		8th and 10th grade
Findholt et al. (2011)	Obesity/diabetes	Photovoice	✓		✓	✓		15–18 years
Flicker et al. (2004)	Sexual health	Semi-structured interviews	✓	✓	✓	✓		HIV+ youth
Flicker et al. (2005)	Sexual health	Needs assessment, interviews	✓	✓	✓	✓		HIV+ youth
Flicker et al. (2008)	Youth engagement	Development of youth engagement model	✓	✓	✓	✓	✓	11–24 years
Flicker et al. (2010)	Sexual health	Survey development	✓	✓	✓	✓	✓	13–17 years
Foster-Fishman et al. (2010)	Youth engagement	Photovoice, community exhibition		✓	✓	✓	✓	Middle-schoolers
Gadin et al. (2009)	General health	Youth proposals for health interventions		✓				Grades 1–6 (7–12 years)
Gulati et al. (2011)	General health	Critical ethnography, focus groups	✓		✓			12–18 years
Horn et al. (2008)	Substance use	Intervention development	✓		✓			Youth
Jackson et al. (2010)	Obesity/diabetes	Theater-based intervention	✓	✓	✓		✓	6th–8th grade
Johnson et al. (2010)	Safety/violence	Multi-method needs assessment		✓	✓	✓		University students
Kellet (2010)	Youth engagement	One 11 year old girl's independent research		✓	✓	✓	✓	11 years
Leipert et al. (2011)	General health	Photovoice		✓	✓	✓		12 and up
Lipman et al. (2011)	Obesity/diabetes	Community-based clinical research	✓	✓	✓	✓	✓	10th graders
Loh et al. (2002)	Environmental health	Developing education dissemination tools	✓	✓	✓			High schoolers
Maconochie and McNeil (2010)	Youth engagement	Multi-method "Mosaic" approach	✓	✓	✓			Babies—4 years
Maglajlic (2010)	Youth engagement	Youth PAR groups administered surveys	✓	✓	✓	✓		12–14 years
Mance et al. (2010)	Mental health	Intervention development	✓	✓	✓			Young adults
Mathews et al. (2010)	Wellness	Intervention development	✓	✓	✓	✓	✓	13–15 years
Meininger et al. (2010)	Obesity/diabetes	Students facilitated groups to collect data	✓	✓	✓			High school/college
Mendenhall et al. (2011)	Substance use	Surveys, intervention development	✓	✓	✓	✓	✓	Age 16–24
Mooney-Somers, et al. (2009)	Sexual health	Youth recruiters, Interviews	✓	✓	✓			Young men and women

Table 1 continued

Reference	Broad content area	Design/methods	Phases of youth involvement					Age of youth
			1	2	3	4	5	
Morsillo and Prilleltensky (2007)	Wellness	Development of various interventions		✓	✓	✓	✓	15–21 years
Necheles et al. (2007)	General health	Photovoice, advocacy projects		✓	✓	✓	✓	'Teen' or 'adolescent'
Oliver and Hamzeh (2010)	Physical activity	Group discussion sessions, photovoice		✓	✓	✓	✓	5th grade
Ozer et al. (2008)	School environment	Surveys, policy change advocacy		✓	✓		✓	High-school students
Ozer et al. (2010)	School environment	Photovoice	✓	✓	✓	✓	✓	6–8th grade
Perry and Hoffman (2010)	Physical activity	Focus groups, surveys	✓	✓	✓			"Youth"
Peterson et al. (2010)	Safety/violence	Focus groups, surveys	✓	✓	✓		✓	13–19 years
Porter et al. (2010)	Wellness	Photo diaries, interviews, mapping		✓	✓	✓	✓	Children 14 and under
Ren and Langhout (2010)	School environment	Researcher-led focus groups & observation	✓	✓	✓			K–5th grade
Rosen-Reynoso et al. (2010)	School environment	Intervention development	✓	✓	✓	✓	✓	High school youth
Snider et al. (2010)	Safety/violence	Concept mapping		✓	✓	✓		12–24 years
Soleimanpour et al. (2008)	School Environment	Surveys, advocacy for policy change	✓	✓	✓		✓	Mostly 8th–11th graders
Stewart et al. (2008)	Wellness	Interviews, youth-created videos		✓	✓	✓	✓	High school students
Streng et al. (2004)	Wellness	Photovoice		✓	✓	✓	✓	High school students
Tharenos and Santorino (2009)	Physical activity	Photography, surveys, interviews			✓			15–20 years
Trinidad (2009)	Wellness	Researcher-led interviews				✓		18–21 years
Van Sluys (2010)	Wellness	Student-led ethnography	✓	✓	✓	✓	✓	8th graders
Veinot et al. (2006)	Sexual health	Youth-led interviews, surveys	✓	✓	✓	✓	✓	'youth'
Wang and Pies (2004)	Wellness	Needs assessment, Photovoice	✓	✓	✓	✓		13 and older
Wilson et al. (2006)	Wellness	Youth co-facilitated action groups	✓	✓	✓	✓		High school students
Wilson et al. (2008)	Youth engagement	Photovoice, social action projects	✓	✓	✓			High school students
Yonas et al. (2009)	Safety/violence	Writing, drawing, painting, discussion	✓	✓	✓			Age 8–15
Total: 56 studies			33	43	47	30	29	

Phase 1 = Youth advisors; Phase 2 = Youth identified research goals; Phase 3 = Youth designed/conducted research; Phase 4 = Youth participated in data analysis; Phase 5 = Youth participated in dissemination

Although youth of all ages were represented in the studies partnering with youth, the vast majority (79 %) of youth partners were middle school age or older. Of the 79 % partnering with middle school age or older kids, half exclusively included high school age adolescents as research partners. Only 11 % of studies classified as "CBPR with Youth" specifically described partnerships that included youth in elementary school or younger. Six studies did not include detailed information about the age of youth partners, but described their partners as "youth" or "young men and women".

Discussion

Community-based participatory research has increased substantially in the past decade and has been touted as an effective strategy to engage children and adolescents in the research process, thereby empowering youth to make changes benefiting themselves and their communities (Syme 2001). Although many studies have been described as utilizing a CBPR orientation in research addressing youth issues, great variability exists in the degree to which youth are partners in the true spirit of CBPR. In our analysis of 399 studies described as community-based participatory research with youth, two major findings emerged. First, only 15 % of the literature described in keywords or MeSH terms as related to CBPR and youth actually partnered with youth to conduct research. The majority of studies lacked a partnership component or partnered with adults. Second, within the subset of studies that partnered with youth, the degree to which youth were involved in the research process varied considerably. We will discuss each of these points and provide exemplars of CBPR projects that successfully engaged youth in multiple phases of the research process.

Research that Did not Partner with Youth to Conduct CBPR

The majority of the existing literature did not involve youth as research partners but instead worked with community organizations, partnered with adults, or lacked a partnership component altogether. The largest category of manuscripts reviewed (27 %) was community-placed studies. Typically, studies in the community-placed category collected data or administered an intervention in a community setting. Researchers did not describe the theoretical or logistical reasons behind their research design, but placing research in the community rather than a clinical setting often has the benefit of facilitating recruitment and increasing the likelihood of an ethnically and socioeconomically representative sample. Because traditional

research has taken place almost exclusively in clinical or academic settings, the movement of research into community locales is a significant and some would argue considerably beneficial shift in academic thinking. Placing research in the community increases the potential for typically underrepresented individuals to participate, thereby broadening scientific knowledge to become more applicable to the population as a whole. Despite the benefits of community-placed research, the lack of community *partnership* has several consequences. First, community members are less likely to be empowered to make change through passive participation in research. Without community partnership, the sustainability of research projects is entirely dependent on the interest of researchers, whose primary interest is not community-level change but in academic pursuits. Second, the degree to which scientific data has external validity for the community from which it was collected is questionable because community members are not asked for their perspective. Because the partnership component is the very crux of CBPR, it is important to distinguish research in which academic investigators collect data or deliver interventions in communities from true community-based participatory research.

In contrast to those studies that were community-placed, 10 % of our sample partnered with community members or organizations to conduct research. Community-partnered research most often had direct, tangible benefits to the community; for example, program evaluation (e.g., Coughey et al. 2010), intervention development (e.g., Chomitz et al. 2010) or provision of needed data (e.g., Hill et al. 2007). Although community-partnered research has clear benefits to both community and academic partners, these studies lacked the participatory component of CBPR. Similar to *community-placed* research, *community-partnered* research does not include community members as contributing members in the research process and therefore misses opportunities for sustainability and external validity. Alternatively, community-partnered research allows community members and researchers to function in the roles with which they are familiar, decreasing the time and energy investment and making projects more feasible. As such, community-partnered research appears to be a compromise for investigators limited on time and resources but interested in conducting research that is relevant and beneficial to communities.

Twenty-one percent of the studies reviewed were either reviews or primarily descriptive in nature (i.e., case studies, literature reviews, "lessons learned" papers). One of the most commonly cited challenges to conducting CBPR is the time involved in developing partnerships and maintaining relationships (Israel et al. 2006). Many researchers, particularly early-career investigators concerned with promotion and tenure, are pressured to have a publishing

record demonstrating their research activities. Because much of the time on the front end of CBPR projects is devoted to partnership building activities that don't have data documenting outcomes, manuscripts describing the partnership building process are an effective way to disseminate research activities. In addition to publishing pressure, the reflective, iterative nature of CBPR lends itself to more descriptive and qualitative outcomes. As a result, "lessons learned" papers are more common in CBPR than with traditional research, allowing investigators interested in utilizing CBPR strategies to gain insight into the logistics of partnering with community members in the research process.

In our literature search for CBPR and youth, we identified more studies that partnered with adults (27 %) than with children (15 %). Sixteen percent of studies partnered with adults on research designed to benefit adults, communities, and families. In this context, adults are the ideal partners because the content of the research is at least partially focused on the health and well-being of other adults. An additional 11 % of the reviewed literature focused on studies partnering with adults about youth issues. In many ways, adult partnerships are an effective way to address youth problems because parents are highly invested in bettering the environment of their children. In fact, in many situations adults have more motivation to make positive changes in lives of children than children themselves. For example, the developmental tendency to consider oneself invincible to health problems might lead youth to deemphasize the need for interventions addressing obesity, HIV/AIDS, or teen suicide; however, we know that these problems affect youth and CBPR with adult/parent partners could help us develop interventions that are contextually appropriate.

Although CBPR with adults can be an effective strategy to address youth issues, collaborating with youth as co-researchers has several added benefits. CBPR has been identified as particularly effective with marginalized communities because it takes the power imbalance out of the research process (Postma 2008). CBPR with youth is no exception. In most traditional research, children and adolescents are included as participants rather than partners and are studied rather than studying. When youth and researchers are each valued for their unique contributions and decision-making is shared, research has the added benefit of empowering youth as agents of change. Research that is conducted by youth is more likely to be accepted by other youth, increasing the chance that the results will create change in youth behavior (Powers and Tiffany 2006). In addition, research is enriched by the contextual knowledge that only youth as "experts in their own lives" can provide, enhancing the likelihood that results will be meaningful and valid (Langsted 1994).

CBPR Studies with Youth

The 56 studies that partnered with youth to conduct CBPR varied considerably in both the content of the research and the way in which youth were involved. As in the adult literature, CBPR was most commonly used to address issues related to health and wellness. Although other community-partnered work is becoming more visible in areas like psychology and education, CBPR as a viable, rigorous approach to research has been more readily accepted in public health and health promotion than in other disciplines. In particular, CBPR is a popular approach to addressing health disparities because partnering with community members increases engagement and acceptability over traditional research approaches (Israel et al. 2005).

Whereas the content areas represented by the CBPR with youth studies varied considerably, the methods and research design strategies utilized in these projects were even more diverse. Several studies worked with youth to develop and administer assessment tools typical to traditional research, like surveys (e.g., Perry and Hoffman 2010; Veinot et al. 2006) and anthropomorphic measures (e.g., Bardwell et al. 2009). Many other studies utilized methods popularized by CBPR practitioners, like Photovoice (e.g., Foster-Fishman et al. 2010; Necheles et al. 2007) and the multi-method "Mosaic" approach (e.g., Clark 2010). The diversity in methodology utilized with youth in these 56 projects speaks to the oft-cited dictum in participatory research that CBPR is not a methodology in and of itself but an orientation to research that values community participation and shared decision-making (Cornwall and Jewkes 1995; Minkler and Wallerstein 2008). In about 77 % of the *CBPR with youth* studies reviewed, youth were involved in identifying the research priorities and/or questions and in about 84 % youth were involved in designing and/or conducting the research plan, indicating that children and adolescents have been active, contributing participants in the research process. These results suggest that those studies that partner with youth to conduct research are most often engaging youth in making decisions about research design and that the resulting methodology provides rich, creative data that is relevant to youth communities.

Although ages of participating youth ranged considerably, 79 % of studies partnered with middle school-aged youth or older. In fact, 39 % of studies only included high-school aged adolescents as participants. By its very nature, CBPR requires community partners to take an active role in research tasks, which requires critical thinking about the environment and the research process. Because classic Piagetan theory suggests youth do not develop the critical thinking skills necessary to engage in scientific reasoning

until middle childhood (Piaget 1973), it is not surprising that youth-partnered CBPR efforts are fairly rare in younger children. Despite the cognitive development of pre-school aged youth, some researchers argue for the importance of including youth children as co-researchers in order to make meaning from research (Clark 2010; Rogoff et al. 2001). For example, Clark and Moss have outlined the Mosaic Approach, a multi-method participatory strategy that incorporates visual and verbal techniques to engage young children in research (Clark and Moss 2011). Proponents of CBPR with young children argue that like all individuals, young children are "experts in their own lives" (Clark 2010; Langsted 1994); therefore, research targeting children's lives is without meaning if it does not reflect the youth perspective. In one notable example, researchers have used the Mosaic approach with children as young as infants by observing nonverbal behavior to identify likes and dislikes and checking perspectives with parents and older siblings (Maconochie and McNeil 2010). The relative rarity of children younger than six in CBPR with youth studies suggests that future research is needed to identify and promote age-appropriate research strategies, to determine the degree to which CBPR with young children can still be scientifically rigorous, and to examine barriers that academic partners have to including young children as co-researchers.

In our review of the literature partnering with youth on CBPR projects, several studies stood out as exemplary portrayals of successful engagement of youth in research. We have chosen two articles that included youth in all five of our identified phases of research, representing every step of the research process. We have not chosen these articles to suggest that they are the only successful examples of CBPR with youth or that only research that includes youth in every step is "successful." We intend to highlight exemplars that have successfully engaged youth in research in two different content areas using innovative methods and designs.

Girls Study Girls, Inc.

Chen and colleagues describe a 4-year participatory evaluation project conducted within the nationwide nonprofit organization Girls, Incorporated (Chen et al. 2010). Since 1945, Girls Incorporated has worked with primarily low-income and minority girls to provide research-based programs to empower and educate young women. As an organization, Girls Inc., emphasizes involving girls in positions of power and leadership. Girls serve on boards and advisory committees and are treated as equal partners with adults. In the face of increasing demand for evaluation of Girls, Inc., programs, the organization decided to involve girls at affiliate agencies in a participatory

evaluation effort. The evaluation, called Girls Study Girls, Inc., included four stages: research training, data collection, data analysis, and dissemination, which correspond to Phases 2–5 of our research categorization system. Girls first learned research skills that enabled them to create their own research questions and action plans. They collected data in the form of photographs and interview questions and then reviewed and analyzed the data. Finally, girls created reports and presentations that they presented to their peers, local communities, local organizations, and the national Girls, Inc., office. At each stage of the research process, adults supported youth as they led evaluation efforts and made decisions about how to conduct the evaluation.

The results of Girls Study Girls, Inc., highlighted major themes about the factors that make the program valuable for girls, including a sense of connection, availability of resources and opportunities, and supportive environments that enhance self-confidence. Girls also were able to identify areas of concern specific to their affiliate organization, which affiliates used to make improvements. Girls Study Girls, Inc., as an exemplar highlights how young women can be engaged in research not only as experts in their own experience but also as investigators into their own research questions. Chen and colleagues noted that the adult staff learned an important lesson through their participation in the project: "instead of focusing on what girls can do at a particular age…adults need to focus on how to create an environment that can help girls stretch beyond their current ability and continue to grow" (Chen et al. 2010, p. 234). Girl Study Girls, Inc., also serves as an excellent example of how to incorporate youth as partners into an existing organization traditionally run solely by adults. By partnering with girls on the project, Girls Inc., was able not only to conduct an evaluation of their program but also to simultaneously address the organization's overarching aim of empowering young women.

OPT4College

Whereas Girls Study Girls, Inc., utilized a participatory strategy with youth to evaluate an existing program, OPT4College is a youth-based participatory research project with the goal of creating a curriculum to support youth with disabilities who are transitioning to post-secondary education (Rosen-Reynoso et al. 2010). The research team, many of whom had physical or learning disabilities or special health care needs, consisted of 6 adults, 12 youth, and 3 graduate students. A group of 15 parents representing diverse immigrant populations provided consultation. A Youth Advisory Board (YAB) made up of youth disability advocates met quarterly to advise intervention development (meeting the criteria for Level 1 of our

categorization system). Through an iterative process, the research team created intervention materials, piloted the materials with the YAB, redesigned the materials based on feedback from YAB and parent consultants, and then re-piloted the new materials. This process was repeated several times, so that what began as a series of 30 min newscast videos transformed into a 6-lesson online curriculum with videos, quizzes, animations, instructional text, and resource pages. The video portion of the final curriculum featured racially and ethnically diverse youth and youth with visible disabilities.

We have chosen the OPT4College project as an exemplar because it is a realistic portrayal of both the costs and the benefits of a true partnership with youth at every level of the research process. Rosen-Reynoso and colleagues are careful to point out that working with youth through several iterations of the "gather data, design intervention, get feedback, redesign intervention" process can be time-consuming and frustrating. For example, the research team created a series of videos featuring youth discussing information about medical transitions to college. They presented the videos to youth from community-based organizations, who said the format was inappropriate, the content was possibly unhelpful, and the videos were generally not "cool". The research team then spent several months gathering data through interviews and focus groups to determine what kind of information would be most helpful and which format would be most relevant to adolescents with disabilities. The research team completely redesigned the intervention based on this data and re-piloted it with youth. Although the authors describe the challenges of using partnering with youth on this project, they also are clear that the benefits of using a youth-based participatory research orientation far outweigh the costs. The resulting curriculum not only was created by youth, but also was entirely based on feedback from youth and community consultants rather than on journal articles or theory. Through the many rounds of participatory feedback, the resulting curriculum was adapted in several ways (including level of language, race and ethnicity of actors, format of presentation, etc.) to be contextually appropriate to youth with disabilities transitioning to college.

Future Directions

In this literature review, our goal was to identify manuscripts that were considered by the author or by the academic community to be community-based participatory research with youth. Almost 400 manuscripts were identified and analyzed according to the degree to which academic researchers partnered with youth in the research process. Despite the strength of the review, several limitations should be noted. First, our search terms might have

inadvertently excluded some studies that might be considered CBPR but the authors or MeSH keyword/topic indexers did not identify the work specifically as community-based participatory research. For example, Photovoice is a fairly commonly methodology used in CBPR approaches with youth (Wang and Burris 1997). Although partnering with children and adolescents to use photos to understand youth issues certainly falls within the scope of our research questions, many of these articles might have been excluded because authors use Photovoice as a keyword rather than CBPR. In fact, a project conducted by one of the current authors using Photovoice to partner with youth was not included in our analysis (Vaughn et al. 2008).

Further complicating CBPR nomenclature is that the practitioners tend to use various descriptive terms to describe work in which non-academic partners are involved in the research process, such as *participatory action research*, *community-engaged research*, *participatory research* and *action research* (Viswanathan et al. 2004). The decision of which descriptive word(s) to use appears to vary by academic discipline. For example, the terms *action research* and *participatory action research* are based on the work of psychologist Kurt Lewin in the 1940s and more commonly appears in humanities, education and related fields (Lewin 1946). *Community-engaged research* and *community-based participatory research* are more common in the health-related disciplines (Minkler and Wallerstein 2008). In our review of the literature, we observed that CBPR has been increasingly used by studies to describe research in which community members are involved in the research process. To determine how the term CBPR has been used historically, we did a search using CBPR as the only search term (minus child, youth, or adolescent) and found that 70 % of the total articles with CBPR as a descriptor have been published since January 2007 and 94 % since the year 2000. This suggested to us that CBPR is a relatively new term but is increasingly being used to represent a distinct concept.

The current work was also limited by the lack of description of research methodology available in many published journal articles. Several articles, particularly those published in more medically focused journals, had only short paragraphs describing how research was done. Many authors used the passive voice to describe the research process (e.g., "responses were coded for main themes"), making it impossible to know who actually did the work. It is possible that we excluded papers from the "CBPR with youth" category that actually did partner with youth to conduct different phases of the research process because the article did not describe project roles. Future authors would contribute significantly to the dissemination of youth research efforts by better describing youth

involvement. Alternatively, some community-academic partnerships have chosen to write multiple articles for each project, with some devoted to results and others devoted to the process of partnering with youth (e.g., Flicker et al. 2010).

Finally, we approached the current review with the goal of understanding how youth were impacted by their participation in CBPR projects. Unfortunately, we were unable to analyze youth perspectives of personal engagement or growth as a result of partnering in research because most studies do not assess these outcomes. Although researchers often remark on the empowerment their youth partners experience through the research process, measures of these outcome variables are rare. One avenue that might be promising for investigators interested in youth engagement outcomes is the Positive Youth Development (PYD) perspective. Like CBPR, PYD is a strength-based approach that maintains the assumption that youth are not "problems to be fixed but resources to be developed" (Lerner et al. 2005). PYD researchers have investigated youth participation in community organizations and have identified the five "C's" of PYD that serve as mechanisms to positive youth outcomes: competence, confidence, connection, character, caring, and compassion (Lerner et al. 2005; Roth and Brooks-Gunn 2003). In order to understand the impact CBPR involvement has on youth, future research might assess the degree to which PYD's 5 C's are manifested in youth partnered CBPR projects.

Conclusions

Although it is not uncommon for youth-related research to be called CBPR, it is much less common for researchers to partner with youth in the research process. Studies are more often community-placed or partnered with adults to address youth issues. Because CBPR is still relatively new and is still in the process of gaining acceptance by the academic community and funding organizations, it is important to preserve a clear definition of CBPR as research that has a participatory component and adheres to the values of collaboration and engagement. Researchers who have partnered with youth have realistically described the challenges in terms of time and effort, but overwhelmingly describe the benefits of these experiences as outweighing the costs, in terms of both research quality and youth empowerment. The potential for youth to be involved in the research process is seemingly limitless. Whereas some studies have involved youth at one stage of research, many researchers have effectively incorporated youth into every stage. Future researchers interested in innovative methods to engage youth can find a wealth of ideas in the 52 reviewed studies on CBPR with youth.

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