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Review of Community-Engaged Research in Pediatric Diabetes

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Abstract

Purpose of Review—Community-engaged research (CER), which is characterized by collaborations between researchers and community partners, is a promising approach to bridge the gaps in translating research evidence into care settings and to address health disparities. This review describes CER in investigations focused on pediatric diabetes.

Recent Findings—Studies were focused on African American, Hispanic, and Native American youth. Most studies aimed to develop and evaluate preventive interventions for type 2 diabetes. Across studies, the community partners and organizations that collaborated with researchers were diverse (e.g., youth, schools). In most studies, community partners participated in developing behavioral, psychosocial, or public health interventions, and/or participant recruitment. Fewer studies reported intensive involvement in other aspects of the research (e.g., grant writing, publication).

Summary—The findings suggested that CER is a feasible approach for engaging community partners in the development of interventions and participant recruitment in studies focused on diabetes among minority youth.

Keywords

Community-engaged research; Community-based participatory research; Type 1 diabetes; Type 2 diabetes; Pediatrics; Youth

Introduction

A number of studies have documented the persistent racial/ethnic disparities in the prevalence, health status, and mortality in type 1 and type 2 diabetes in children and youth. African American, Hispanic, and Native American youth have a higher prevalence of type 2 diabetes (T2D) [1, 2]. Moreover, among youth with type 1 diabetes (T1D), African Americans and Hispanics have disparities in health status that consists of poorer glycemic

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control and higher rates of diabetic ketoacidosis and hypoglycemic events [3–5]. Of particular concern is the persistent higher diabetes-related death rate among African American youth [6]. In addition to these disparities among particular racial/ethnic minority groups, gaps in the translation of research evidence into diabetes care settings appear amplified for African Americans and Hispanics. For example, these groups are less likely to be treated with an insulin pump or other diabetes technology to manage T1D compared to non-Hispanic white youth, even when they have similar insurance or incomes [3, 7, 8]. All of these findings point to the need for more research related to diabetes in order to promote health equity among African American, Hispanic, and Native American youth.

Community-engaged research (CER) has emerged as a promising approach to address health disparities and the gaps in the translation of research evidence into health care and in community settings [9–12]. Additional proposed advantages of this approach include enhancing the ability of researchers to include critical community insights into research questions or data interpretation, designing culturally and language-appropriate interventions, and increasing research recruitment and representation of understudied populations [13]. CER is characterized by collaborations between researchers and community partners [13, 14]. Community partners in CER can be diverse and may include youth with diabetes and their families, diabetes care providers (physicians and school nurses), community-based organizations (schools and public health departments), or community advocates (advocates from diabetes-focused foundations) [14].

CER is also depicted by a continuum of community engagement that ranges from less intensive to more intensive community partner participation [14]. Less intensive involvement is defined as community partners assist in discrete steps of a researcher-designed study, such as participant recruitment. Involvement of medium intensity is defined as community partners act as subcontractors in the researcher-designed study by engaging in a defined set of multiple responsibilities, such as participant recruitment, data collection, and providing feedback on aspects of the study design. Engagement of high intensity is defined as the researcher and community partners enter into a partnership to jointly design a study that explores a problem of shared interest and to equitably share resources and findings. Community-based participatory research (CBPR) is considered the mostly actively community-engaged model of CER [11, 14]. CBPR includes co-learning and reciprocal transfer of expertise, shared decision-making power, and mutual ownership of the processes and products of investigations [15]. Although CER holds promise to accelerate the translation of research findings and address health disparities in pediatric diabetes, a number of challenges to this approach have been described, which may limit its use in diabetes research.

Barriers to CER include time-intensiveness and low availability of funding to establish and maintain effective partnerships with researchers, and community partners, the limited understanding of and preparation for the demands and requirements of each other's research or practice (e.g., research protocol requirements might clash with community-based organizations' focus on service provisions), and misalignment of academic and community partner priorities [13, 14]. For diabetes research, misunderstandings and low awareness of the differences between type 1 and type 2 diabetes present additional barriers to community

engagement. Despite these challenges, CER has been used in studies that evaluated interventions among adults with diabetes. Community-based physical activity interventions and interventions delivered by community health workers to promote health behaviors and improve glycemic control have been evaluated in CER focused on adults with T2D [16, 17]. Community partners in these studies have assisted with participant recruitment, facilitated use of community-based locations for intervention implementation, and delivered intervention components. Although these studies have demonstrated the feasibility of researcher-community collaborations to concentrate on diabetes in adulthood, a unique consideration for CER focused on pediatric diabetes is the involvement of children and youth as community partners. CER studies in pediatric diabetes may need to consider community participation by adults or youth, or both. Further, the roles of youth in CER may differ from adults given that low motivation, increased competing demands/interests, or very limited knowledge of research may impede participation by youth [18]. However, little is known about CER concentrated on diabetes among children and youth.

Purpose of the Review

The purpose of this review is to describe the current literature that implements CER in investigations of pediatric T1D and T2D. We also provided an example of CER from our ongoing study [Type 1 Diabetes Empowerment and Management; (TEAM study)] that uses this approach to develop and evaluate a family- and community-based intervention for African American and Latino parents of children with T1D. Finally, recommendations for future CER focused on youth with diabetes are provided.

Description of Studies Using CER in Pediatric Diabetes

Studies Focused on Prevention of Type 2 Diabetes Among Youth

The Diabetes Prevention Program is an evidence-based group intervention designed to prevent the onset of type 2 diabetes in adults at elevated risk. Two CER studies aimed to adapt the adult Diabetes Prevention Program for youth. The first study focused on adapting the program for children ages 9–12 years in a YMCA setting, where members were 67% Hispanic [19•]. Community partners included an Advisory Board of experts on diet, physical activity, youth development, diabetes, mobile technologies, and pediatric medicine; youth 9–12 years of age; administrators and program staff of the YMCA; and staff from a Cooperative Extension nutrition education program. Community partners informed the intervention design through multiple steps. Qualitative interviews were conducted with YMCA administrators and staff to determine factors influencing local adoption. Researcher Advisory Board meetings were held to obtain Advisory Board members' initial feedback on the intervention materials, and user tests of the intervention were conducted with youth 9–12 years of age using qualitative methods. Advisory Board members reviewed qualitative findings from youth and provided recommendations for final adjustments to the intervention. Overall, intervention adaptations included (1) inclusion of content that was relevant to youth and families (e.g., “parent-only” discussions to promote positive parenting practices, such as role modeling), (2) addition of digital intervention components delivered via mobile devices

(i.e., study-provided tablets), and (3) in-person intervention components delivered by trained YMCA paraprofessionals.

In contrast, the second study that focused on adaptation of the adult Diabetes Prevention Program involved more intensive community partner participation. Researchers used CBPR to adapt the program to be age and culturally specific for American Indian youth [20]. A partnership was formed between academic researchers, tribal health center staff and clinicians, and tribal health board and council members from reservation communities to prepare and submit a National Institutes of Health (NIH) grant application. Academic researchers and community partners collectively wrote the grant proposal and established a Code of Research Ethics for the partnership and research study. Decisions about the study design, participant recruitment, evaluation, and planning for long-term sustainability were made jointly. Community partners assisted with recruitment by identifying American Indian youth and adults to complete qualitative interviews to determine facilitators of and barriers to healthy eating and physical activity, and diabetes prevention awareness in order to inform them of intervention adaptation. Community partners, rather than research staff, were also trained to conduct the qualitative interviews.

Other studies have developed new preventive interventions for T2D. One study used CER to develop and implement a prevention campaign targeting social and environmental risk factors for T2D (e.g., affordable food and safe areas for physical activity) [21••]. Academic researchers partnered with a nonprofit organization that addressed youth development through promoting spoken word and literacy. The community partners in this study were adolescents and young adults 16–24 years of age from the nonprofit organization, most of whom were identified as Latino or African American. Their role in the study included creating the campaigns' public service announcements after receiving education from the academic researchers about the prevalence of T2D in communities, social and ethnic disparities in prevalence and complications, and environmental contributors to T2D (e.g., food and beverage policy and advertising practices).

Another study used CBPR to develop and implement a physical activity intervention to reduce T2D risk factors in elementary school-aged (kindergarten to 8th grade) American Indian youth [22]. Academic researchers partnered with the Health Department of an American Indian tribe and school personnel. Academic researchers and staff from the Health Department collaborated for more than 20 years prior to the onset of this study. Decisions about research design and methods (e.g., selection of research outcome measures) were jointly determined by academic researchers and community partners. The community partners implemented the intervention, and research resources (e.g., blood glucose meters) remained the property of the Health Department at the end of the study. It was also reported that the intervention and assessments continued to be implemented by the Tribal Health Department after research funding ceased.

Finally, one study used CER to conduct descriptive research. Academic researchers partnered with high school students to determine elementary-aged children's T2D risk factors, physical endurance, knowledge of nutrition, and parental perceptions about healthy living [23]. The elementary-aged children in the study were African American. The high

school students were trained in data collection procedures and implemented data collection in the study.

In sum, across these five studies focused on the prevention of T2D among youth, most investigations aimed to modify or develop and evaluate an intervention among Hispanics, Native Americans, or African Americans. Notably, three studies included youth (ages 9 and above) as community partners. Their roles consisted of data collection, and informing, designing, or implementing intervention components. Adult partners across the studies were diverse and included community-based organization staff, health center staff and providers, and a local Health Department. These adult partners were more intensively involved than youth in other aspects of the research. They participated with researchers in designing research procedures, and grant preparation and submission.

Studies Focused on Youth With Type 2 Diabetes

We identified one study that was conducted among youth with diagnosed T2D. This study used CER to concentrate on American Indian youth participation in the NIH-funded Treatment Options for Type 2 Diabetes in Adolescents and Youth (TODAY) study, which aimed to determine optimal treatment in youth who were newly diagnosed [24]. Academic researchers partnered with the Oklahoma City Area Indian Health Services and several Oklahoma tribes and nations. A Native American Coordinator position was created as part of the grant application. The coordinator fostered relationships between the researchers and community partners, facilitated a Memoranda of Agreement between the partners, and ensured that American Indian interests were adequately represented in the study. Additionally, intervention leaders and the study physician were American Indians, and the study authors reported that this contributed to adequate rates of screening, recruitment, and retention of American Indian youth. American Indian Institutional Review Boards required review and approval of all research presentations and publications.

Studies Focused on Youth With Type 1 Diabetes

We identified two studies focused on youth with T1D. One study involved relatively less intensive community participation. In this study, researchers collaborated with bilingual Latino parents of children with T1D to determine their perspectives on the appropriateness of culturally adapting an established intervention to increase social support among Latino parents of children with newly diagnosed diabetes [25]. After receiving feedback from Latino parents in support of cultural adaptation, qualitative interviews were completed with parents to determine their recommendations for adapting the intervention. Suggestions for cultural adaptation included offering resources in Spanish and English, providing access to diabetes education on preparation of healthy cultural traditional foods, and offering resources for bilingual taxi services.

A second study used more intensive community participation in T1D research. This study compared the effectiveness of family centered tailoring of diabetes self-management resources to usual care among youth with T1D (ages 8–16 years) and their parents [26]. Qualitative interviews were conducted with clinicians, clinic leadership, clinic schedulers, medical assistants, and patients' families to determine potential challenges and solutions

related to study procedures and intervention implementation. Separate parent, youth, and teen advisory boards were also established. A fourth advisory board consisting families, clinicians, clinic administrators, and representatives from community diabetes advocacy groups was also created. Advisory board members guided successful study implementation, provided solutions to challenges with recruitment, retention, and integration into the clinic, interpreted study findings, and facilitated dissemination. The authors noted that they achieved high recruitment rates among populations that are typically thought of as hard to research for research participation (e.g., racial/ethnic minority families and families with less educational attainment). Table 1 provides an overview of the reviewed studies. Below, we describe our ongoing research that uses CER concentrating on children with T1D and their families.

Type 1 Diabetes Empowerment and Management (TEAM) Study

The TEAM study is an example of CER in an ongoing project funded by the NIH/National Institute on Diabetes, Digestive, and Kidney Disorders (DP3DK113236). The research aims to use a community-engaged approach to develop a family- and community-based behavioral intervention for African American and Latino parents of children 5–9 years of age with T1D who are served by a local diabetes care center. The feasibility and preliminary outcomes of the intervention will be evaluated using a randomized pilot trial design. The investigator team consists of psychologists and pediatric endocrinologists who provide care in a large diabetes care center that serves racially/ethnically diverse children and youth. Community partners include extension agents from a local Cooperative Extension Program; Public Health Practitioners, a community-based Chief Nurse/Certified Diabetes Educator, Manager of the Multiservice Centers from the City of Houston Public Health Department; other diabetes care providers from the diabetes care center; and African American and Hispanic parents of children with T1D.

The community engagement process was initiated by the Principal Investigator of the study before submission of the grant application. The barriers of time-intensiveness and low availability of funding streams to initiate partnerships for the grant application were minimized because of the PI's previous relationships with the Prairie View A&M University Cooperative Extension Program and Public Health Department. The PI initiated meetings with the Health Coordinator from a local Cooperative Extension Program and the Director of the Houston Health Department to discuss shared interests in pediatric diabetes and the idea for a grant application. After these meetings, the team of study investigators prepared the grant application, which included letters of support from the Cooperative Extension Program and the Houston Health Department. After grant funding was obtained, the endocrinologist investigators also identified parents of children with type 1 diabetes and other diabetes care providers who could serve as community partners in the research. Overall, the community partners were chosen to (a) help overcome the barriers of cultural mistrust and socioeconomic barriers that often impede minority family participation and retention in intervention research by holding recruitment events and intervention sessions in community-based public health settings and (b) design a culturally appropriate behavioral intervention. Table 2 lists the community partners and their involvement in the study.

At the outset of the study, the investigator team of psychologists and endocrinologists also sought message mapping consulting services from a firm experienced in communications for local government and community public health organizations to address the challenges of misalignment of academic and community partner interests, priorities, and communication practices in CER. The purpose of message mapping was to create compelling, relevant messages about the study for the various community partners and potential research participants. Message mapping in our study also serves as a strategy to ensure messages about the projects are delivered consistently among the research team and the various community partners. Deliverables from the consulting service included (a) formalized mission and vision statements to guide researcher communications with community partners and within the research team, respectively, (b) study branding suggestions to use bold colors and racially/ethnically inclusive images for study materials, and (c) the suggestion to use the terms “African American/Black” and “Hispanic/Latino” in all study materials to include inclusive terminology for the families we intend to enroll in the study.

We are currently implementing the design phase of this project. In this phase, community partners will inform the adaptation of Family Teamwork, an evidence-based behavioral intervention for improving glycemic control in early adolescence, by targeting parents of school-aged children. Community partners will provide feedback on intervention materials in an iterative manner. Qualitative interviews with parents will be conducted to identify barriers to involvement in T1D management for each racial/ethnic group to further refine the adapted and integrated intervention. Meetings with community partners will be convened to provide the partners with results from the qualitative interviews and obtain feedback on refining the intervention based on the findings. Subsequently, in the pilot trial phase of the project, community partners will assist with the implementation of “Research and Education Day” events to successfully recruit families for the intervention trial. Research and Education Day is a model that has successfully increased the recruitment of minority families of children with sickle cell disease into research studies. During these events, potential participants and other family members will receive information about T1D from diabetes providers, participate in enjoyable and informative health activities (T1D health knowledge games) led by staff from the Cooperative Extension Program and Public Health Department, and receive information about value of research in type 1 diabetes provided by the academic researchers. Parents of children with type 1 diabetes will also lead the intervention that will be created. Through our use of CER, we will determine whether separate interventions will be created for African/Black and Hispanic/Latino families.

In summary, our project aligns with CER that has medium intensity involvement of community partners, because the study was designed and initiated by academic researchers, yet the community partners engage in multiple project activities. It is our hope that CER results in an intervention that is culturally appropriate and can easily translate to community settings with sustainability after grant funding has ended.

Conclusions

Overall, our review of the literature indicated that most studies using CER in pediatric diabetes have focused on the prevention of T2D compared to addressing youth who have

been diagnosed with diabetes. Studies also concentrated on African American, Hispanic, or Native American/American Indian communities, which are groups with persistent disparities in diabetes. Across all studies that we identified, community partners have been diverse and included racial/ethnic minority youth and parents, healthcare providers, and different community organizations, including a YMCA, school, public health departments, nonprofit youth organizations, and university-based Cooperative Extension Programs. When youth engaged as community partners, they received training, education, and/or incentives, such as course credit, to support their role in investigations. Finally, the level of community involvement in studies ranged from low intensity to high intensity (i.e., CBPR) with community partners engaging in intervention design and/or participant recruitment in most studies. Studies with the most intensive CER, as evidenced by the use of CBPR, were concentrated on Native American youth. This might be due to the need for intensive strategies in order to successfully overcome in Native American communities, mistrust of research, a history of research findings not being shared with Native American communities, and a history of no perceived benefits from research participation. The findings suggested (a) the feasibility of CER in pediatric diabetes research to develop interventions for racial/ethnic minority youth and (b) youth can engage as partners with educational support and strategies to bolster motivation. Future studies should report the sustainability or dissemination of interventions that have been designed and implemented using CER to help determine whether this approach facilitates translation into diabetes care or community settings.

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• Of importance

•• Of major Importance

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Table 1

Description of studies using CER in pediatric diabetes

Study authors	Study aim	Community partners	Community partner involvement
Hingle, Turner, Kutob, Merchant, Roe, Stump et al., (2015) [19•]	Adapt the adult Diabetes Prevention Program for children in a YMCA setting	Experts on diet, physical activity, youth development, diabetes, mobile technologies, and pediatric medicine Youth 9–12 years of age Administrators and program staff of the YMCA Staff from a Cooperative Extension nutrition education program	Informed intervention design and materials
Brown, Harris, Harris, Parker, Ricci, & Noonan (2010) [20]	Adapt the adult Diabetes Prevention Program to be age and culturally specific for American Indian youth	Tribal health center staff and clinicians, Tribal health board and council members from reservation communities	Participated in preparation and submission of NIH grant application Helped Establish Code of Research Ethics Assisted with decisions about study design, participant recruitment, evaluation, and planning for longer term sustainability Assisted with participant recruitment Received training in qualitative interview methods Conducted qualitative interviews
Rogers, Fine, Handley, Davis, Kass, & Schilling (2017) [21••]	Development and implementation of a prevention campaign targeting social and environmental risk factors for T2D	Nonprofit organization that addressed youth development through promoting spoken word and literacy	Received education about T2D prevalence, disparities, and environmental contributors Created campaigns' public service announcements
Teufel-Shone, Gamber, Watahomigie, Styuia, Crazier, & Irwin (2014) [22]	Development and implementation of a physical activity intervention to reduce T2D risk factors	Health Department of an American Indian tribe School personnel	Participated in decisions about research design and methods Implemented the intervention
Lipman, Schucker, Ratcliffe, Holmberg, Baier, & Deatrick (2011) [23]	Determine youths' T2D risk factors, physical endurance, and knowledge of nutrition, and parents' perceptions of healthy living	High school students	Trained in data collection procedures Implemented data collection
Chadwick, Copeland, Daniel, Erb-Alvarez, Felton, Khan et al., (2014) [24]	Concentrate on American Indian youth with T2D participation in the TODAY study focused	Oklahoma City area Indian health services Several Oklahoma tribes and nations American Indian Institutional Review Boards	Native American coordinator fostered relationships between researchers and community partners Engaged in creation of a Memoranda of Agreement between academic-community partners Assisted with participant recruitment Reviewed and approved research presentations and publications
Sullivan-Bolyai (2009) [25]	Culturally adapt an existing intervention for Latino parents of children with newly diagnosed T1D	Latino parents of children with T1D	Informed intervention design
Fiallo-Scharer, Palta, Chewing, Wysocki, Wettemeck, & Cox	To compare the effectiveness of family-centered tailoring of diabetes self-management resources to usual care among youth with T1D and their parents	Clinicians Diabetes clinic leadership and schedulers Medical assistants Parents of children with T1D Youth with T1D Representatives from diabetes advocacy groups	Informed study procedures and intervention implementation Assisted with interpretation of study findings Facilitated dissemination

Table 2
Description of community partner involvement in the TEAM (Type 1 Diabetes Empowerment and Management) study

Community partner	Study participation
Cooperative Extension Program extension agents	Provide feedback on the cultural appropriateness of intervention components Participate in research recruitment events by engaging families in enjoyable health activities
Public Health Department	Provide feedback on the cultural appropriateness of intervention components Participate in research recruitment events by engaging families in enjoyable health activities Facilitate access to Public Health Multiservice Centers for intervention implementation in community settings Facilitate access to community resources for resource-limited families
Diabetes care providers	Provide feedback on intervention content
African American and Hispanic parents	Provide feedback on the cultural appropriateness of intervention components Provide suggestions for the design of research recruitment events Implement intervention components