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Community-Based Participatory Research and Human-Centered Design Principles to Advance Hearing Health Equity

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Abstract

Inclusive and equitable research is an ethical imperative. Community-based participatory research (CBPR) as well as human-centered design are approaches that center partnership between community members and academic researchers. Together, academic-community research teams iteratively study community priorities, collaboratively develop ethical study designs, and co-create innovations that are accessible and meaningful to the community partners while advancing science. The foundation of the CBPR approach is reliant on its core principles of equity, co-learning, shared power in decision-making, reciprocity, and mutual benefit. While the CBPR approach has been used extensively in public health and other areas of healthcare research, the approach is relatively new to audiology, otolaryngology, and hearing health research. Recent applications of CBPR have been framed broadly within the theoretical positions of the socio-ecological model for a systems-level approach to community-engaged research and the Health Services Utilization model within health services and disparities research using CBPR. Utilizing human-centered design strategies can work in tandem with a CBPR approach to engage a wide range of people in the research process and move toward the development of innovative yet feasible solutions. Leveraging the principles of CBPR is an intricate and dynamic process, and may not be a fit for some topics, some researchers' skillsets, and may be beyond some projects' resources. When implemented skillfully and authentically, CBPR can be of benefit by elevating and empowering community voices and cultural perspectives historically marginalized in society and underrepresented within research. The purpose of the current article is to advance an understanding of the CBPR approach, along with principles from human-centered design, in the context of research aimed to advance equity and access in hearing healthcare. The literature is reviewed to provide an introduction for auditory scientists to the CBPR approach and human-centered design, including discussion of the underlying principles of CBPR and where it fits along

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a community-engaged continuum, theoretical and evaluation frameworks, as well as applications within auditory research. With a focus on health equity, this review of CBPR in the study of hearing healthcare emphasizes how this approach to research can help to advance inclusion, diversity, and access to innovation.

Keywords

Community-Based Participatory Research; Human-Centered Design; health equity; academic-community partnerships; social determinants of health; socio-ecological model; Health Services Utilization model; multicultural; audiology; otolaryngology

Health equity is critically important within hearing healthcare and auditory research. Central to the *Healthy People* national public health goals in the U.S. is the overarching goal of eliminating health disparities to achieve health equity across the population (U.S. Department of Health and Human Services, n.d.). Improving the inclusion, diversity, equity, and access in hearing healthcare involves parallel improvements in the research processes. There have also been recent national and global calls for increasing accessible and affordable hearing healthcare to eliminate disparities in access to care (National Academies of Sciences, Engineering, and Medicine, 2016; World Health Organization, 2021).

A high proportion of the growing aging and diverse population in the U.S. is living with untreated or poorly managed hearing loss (Arnold et al., 2019; Nieman et al., 2016; Reed et al., 2020). While the under-diagnosis and under-treatment of hearing loss in the general population is itself poorly understood, even less is known about the accessibility of hearing healthcare among diverse populations, those with low socioeconomic position, and those living in rural communities. In addition, there is limited representation of racial and ethnic minorities within the hearing healthcare workforce (Council on Graduate Medical Education, 2016) and limited representation within auditory research study populations, as evidenced by a recent systematic review of clinical trials in the U.S. on hearing loss interventions for adults (Pittman et al., 2021).

Further, bias may be introduced if the effects of hearing loss on communication, healthcare utilization, and other outcomes are assumed not to be mediated by culture, race, ethnicity, socioeconomic position, as well as other forms of sociocultural identity such as gender, disability, and language. In other areas of health research, this is referred to as the risk of taking a “monocultural view” (Kagawa-Singer et al., 2015). Specifically, this refers to ignoring the potential explanatory power of multidimensional aspects of culture, and the complexities of the social determinants of health.

Community-engaged and participatory research has had a strong role in improving equity and inclusion throughout public health research (Viswanathan et al., 2004), with emerging use in hearing healthcare research. Community-based participatory research, or CBPR, is an approach that involves a key partnership between researchers and the community. Benefits of a participatory approach include the identification of relevant and culturally appropriate research questions, enhanced data collection and interpretation, and facilitating the translation of research findings into action and social change (Wallerstein & Duran,

2010; Viswanathan et al., 2004). Within intervention research, the CBPR approach strengthens both community capacity and community acceptability of the intervention and research study design, leads to practical and feasible research protocols, informs culturally responsive research practices, enhances recruitment and retention strategies, and yields the ability to address health problems resulting from complex interactions of individual, social, cultural, and political factors (Hacker et al., 2012; Jagosh et al., 2012; Macaulay et al., 2011). Taking this approach within hearing healthcare research is at the intersection of disability and issues related to racial/ethnic diversity and systemic racism (Ellis et al., 2020).

Recently a scoping meta-review of community-engaged research and CBPR was conducted (Ortiz et al., 2020). Over 100 reviews in the literature have been published to date within other disciplines including nursing, psychology, public health, and many others, with often interdisciplinary representations of CBPR and participatory research in the literature. However, none of these prior literature reviews had a focus on auditory research or hearing healthcare. The current review aims to address this gap in the literature.

Purpose

The purpose of this article is to provide an introduction to CBPR and human-centered design principles to auditory scientists and describe how these approaches can be applied within auditory research to address issues of inclusion, diversity, equity, and access, ultimately contributing to the elimination of disparities in access to hearing healthcare. In this article, our goal is to advance an understanding of what it means to take a CBPR approach in the context of research aimed to advance equity and access to hearing healthcare. Here we propose that CBPR and human-centered design have potential to offer new perspectives from a broader range of stakeholders, including through principled efforts for greater engagement of, by, and for communities historically marginalized by systemic racism and other forms of oppression. Drawing from the literature, the practices involved in CBPR and its underlying principles, along with human-centered design, will be reviewed. Theoretical and evaluation frameworks, applications within hearing healthcare research, and challenges will also be discussed.

Community-Based Participatory Research (CBPR)

Definition

Viswanathan et al. (2004) reported on a review of CBPR sponsored by the Agency for Healthcare Research and Quality (AHRQ). The purpose of the review was to gather evidence to date in order to begin to develop a more unifying definition of the CBPR approach. Their consensus definition of CBPR describes it as:

> a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change. (pp. 3)

Principles of CBPR

Key principles expanding upon this definition included that CBPR involves co-learning and reciprocity by all partners, shared decision-making power within the academic-community partnership, and mutual ownership of the research process and its outcomes (Viswanathan et al., 2004). An often-cited summary of eight principles of CBPR is attributed to Israel et al. (1998). As summarized in Table 1, these principles of CBPR are found within equitable partnerships between academic researchers and community representatives:

1. Community as a unit of identity;
2. Taking a strengths-based approach building on the community's resources;
3. Equitable and collaborative partnership in all phases of the research;
4. Mutually benefits all partners;
5. Co-learning process that addresses health equity through capacity building and empowerment;
6. Cyclical and iterative process;
7. Considers health from positive and ecological perspectives;
8. Collaborative dissemination of findings within and beyond the community of study.

Rather than a specific research method or set of methods per se, CBPR is an 'approach,' or an 'orientation' to research (Cornwall & Jewkes, 1995). In fact, many different types of study designs have been conducted within a CBPR approach across different disciplines, including randomized control trials and quasi-experimental studies, surveys, and qualitative studies (Clark & Ventres, 2016; De Las Nueces et al., 2012; Salimi et al., 2012). Taking a CBPR approach can include quantitative, qualitative, and mixed methods data collection. However, as we will discuss further in this review, CBPR is emergent in auditory research.

By describing CBPR as an approach or orientation to the research, it is often explained that its underlying principles differ in part from those of traditional laboratory or clinical research studies. An extensive comparison between traditional research and CBPR was carried out by Horowitz et al. (2009) and has been adapted in Table 1. Among the important contrasts between traditional research and CBPR is the degree of community involvement at all stages of the research process, including identifying the research problem, study design and implementation, and dissemination of findings. Taking a CBPR approach will not be a fit for all research topics, researchers' skillsets, and may be beyond some projects' resources. On a practical level, this is exemplified within CBPR academic-community partnerships as equitably sharing project funding, responsibility, and decision-making power. This equitable partnership between researchers and the community of study not only improves external validity, it can lead to action and builds both community and research capacity that can have impact beyond the study itself (Oetzel et al., 2018).

History of CBPR

The history of CBPR as a research approach stems from the social sciences, psychology, and education fields. There are considered to be two major sources of the history of CBPR, the Global Northern and Global Southern traditions, based on their geographic places of origin (Wallerstein & Duran, 2017). The Northern tradition stems from the work of Lewin, a sociology researcher in the 1930s-1940s. The Southern tradition is attributed in part to the work of Brazilian educator and philosopher Paolo Freire, who advocated community empowerment and experiential learning within education research in the 1970s. Wallerstein (2021) explains that the more recent definition of CBPR reflects both traditions. Specifically, this approach includes the iterative research processes proposed by Lewin and others, giving honor to community knowledge and strengths, as well as the emancipatory, social justice focus of the Southern tradition based on the work of Freire and others. Reflecting its growing importance within health research and reducing health disparities, CBPR is now a core area of education in the discipline of public health along with other participatory health research approaches (Wallerstein & Duran, 2017).

Research taking a CBPR approach has been documented globally to address a variety of health issues as well as social justice in education and social sciences research. For example, researchers in South Africa used CBPR principles to establish community priorities around cervical cancer screenings (Mosavel et al., 2005). Researchers in that study used focus groups, interviews, and field visits, to engage community members' feedback and establish partnerships that helped develop a cervical cancer prevention program. The result was a program that emphasized health and wellbeing, rather than pathology (Mosavel et al., 2005). Additionally, the China Jintan Child Cohort Study used a CBPR approach to understand the impact of malnutrition and environmental toxins on the health of children (Liu et al., 2011). In that study, researchers engaged community partners, including parents and teachers, to develop the research protocol, conduct field work, as well as communicate results and engage the public around the topic at health education fairs and poster presentations in local schools and hospitals. The authors conclude that a CBPR approach helped ensure that the topic was relevant to the community and that the protocol was acceptable, and the process helped establish a connection with the community.

CBPR Along the Continuum of Power Sharing in Research

Broadly, CBPR fits within a continuum of power sharing and community engagement in research (Key et al., 2019; Wallerstein et al., 2019). The continuum extends on one end from fully investigator-driven research to the other end with fully community-driven research (Figure 1). The continuum is not only based on who is driving the research question and direction but who and how the power is distributed between the investigator and study team and community representatives. Along this continuum, CBPR is situated towards the highest degree of community involvement and power sharing in research. An element that distinguishes CBPR from other research approaches along this continuum is having community involvement at all stages of the research process (Wallerstein & Duran, 2017). Specifically, this can include community involvement from the earliest stages of assessing and identifying community needs, strengths, and resources; formulating a research question; designing the research study; data collection, analysis, interpretation; to the later stages of

dissemination and identifying new directions for future research. This shared power dynamic is unique to CBPR. These characteristics separate CBPR from the typical approach to investigator-driven study design, as CBPR promotes empowerment and equity by sharing power in all phases of the research with the partnering community. This approach requires having a trusting relationship between academic and community partners, ongoing dialogue and co-learning, and all the while negotiating and balancing the interests of partners (Resnik & Kennedy, 2010; Mohammed et al., 2012). See Figure 2 for methodological approaches to establishing longstanding successful CBPR partnerships.

While CBPR is often recommended, or even solicited by funding agencies, as an approach to engage diverse and vulnerable communities in research, it should not be viewed only as a means to enroll greater numbers of people of color or engage marginalized communities in the research. The CBPR approach emphasizes *equitable partnership* and *reciprocity* with communities to share power within the conduct of the research study itself (Examining Community-Institutional Partnerships for Prevention Research Group, 2006; Shalowitz et al., 2009). Thus, the researcher who takes a CBPR approach recognizes, cultivates, and encourages far greater engagement of community members within the design and conduct of the research study, well beyond the recruitment of participants alone. When investigators recognize the importance of contributions of the community at all stages of the research process, this community engagement enables prioritization and value-shifting that honors the community's needs and strengths. Further, engagement with community partners throughout the entire research process supports a mechanism for accountability so that the research fulfills its intended purpose, while drawing upon the strengths of the community without marginalization or exploitation to be relevant and effective for the communities served.

To expand the CBPR approach within auditory research, we will need both action from individual investigators and systemic supports. It is important for authors/researchers to appropriately represent their work and how it is positioned within the continuum of community-engaged research (see also Figure 1). Additionally, one must not misrepresent research that is conducted within a community setting as CBPR by staying transparent in reporting about the degree to which the study is truly CBPR. Likewise, acknowledging a continuum of community engagement and power-sharing within research, future readers and reviewers of grant proposals and manuscripts within auditory research may do well to watch for indicators of the quality of true CBPR implementation and not mistake community-placed recruitment for CBPR.

There are several key elements to highlight here about the unique process of dissemination of CBPR findings that may be unfamiliar to many auditory researchers. Collaborative authoring of the research studies with community representatives is a hallmark of CBPR dissemination. Co-authorship is intended to be reflective of the research team's respect for community knowledge and substantive contributions provided by community partners within the scientific literature. Specific guidance for researchers about collaboration in authoring of CBPR for peer-reviewed journals with community partners was provided by Bordeaux et al. (2007). Specific recommendations for the dissemination of qualitative CBPR studies has also been outlined by Dolwick Grieb et al. (2014). Also, unintentional systemic

barriers for authorship may exist for community partners. For example, journals may require specific stipulations on what constitutes authorship, which we acknowledge is important to guarantee that there has been a substantive contribution. However, community partners who do not fit the traditional vision of authorship may be omitted from the scholarly process and unacknowledged in the research literature. To date, the question of how to appropriately and adequately represent the work of non-traditional partners in academia remains an unanswered question and represents an ongoing challenge to work towards resolving.

Another hallmark of the dissemination process of CBPR is presenting the study findings to audiences beyond the peer-reviewed scientific literature, in particular, with a focus on dissemination to the partner organizations and partnering community represented. In a systematic review by Chen et al. (2010) about reporting the dissemination of results to the community and general public, it was found that about half of the CBPR scientific publications reviewed included reports about dissemination beyond the peer-reviewed study. In a related survey, they found that authors of CBPR studies published in peer-reviewed journals also reported disseminating results to the participants of the study (98%) as well as to the general public (84%).

Overall, Chen et al. (2010) highlight that the dissemination process beyond the scientific literature has value in reinforcing a number of core principles of CBPR. Specifically, the coproduction of knowledge and its dissemination collaboratively can reinforce relationships and a commitment between the community partners and academic researchers. Dissemination should also serve the community and be of mutual benefit, that is, to share the information back with the partnering community as well as the larger scientific community. The involvement of community representatives can also influence how the information is presented, such as through pieces written for a lay audience or making information available across multiple languages. A potential challenge cited in this regard is that the funding timelines of researchers and community organizations may not adequately account for the additional time and resources needed to effectively and collaboratively disseminate findings within the community and general public. Yet, sustaining these efforts beyond a project's funded timeline can also demonstrate the commitment by academic-community partners to long-term systems level and social change, which may take many years to cultivate beyond a funding cycle.

Culturally-Responsive Practices

Participatory research approaches such as CBPR are of particular interest in cross-cultural and multicultural research. According to González Castro et al. (2006), culturally responsive research "refers to research designs and methodologies that adequately respect the local culture and effectively respond to critical cultural issues" (p. 139). A culturally-responsive approach is essential to CBPR (Wallerstein et al., 2019b). Some researchers have pointed out that there can be overly superficial considerations of culture when evidence-based programs merely undergo literal translations to another language without a more deep-level consideration of culture (Wallerstein et al., 2019b; Resnicow et al., 1999). Culture has been described as a 'missing link' in health research that will help lead to improved outcomes (Kagawa-Singer et al., 2016). An emphasis on a culture-centered approach within CBPR

places a specific focus on community engagement to integrate cultural context and cultural knowledge within research (Wallerstein et al., 2019b). It is argued that CBPR in this way may lead to structural change in research practices and social change through community empowerment.

Cultural Humility

Because the CBPR partnership often brings together individuals from different backgrounds, CBPR calls for researchers to be reflexive about their positions of power, and embrace a perspective of cultural humility (Minkler, 2004). Cultural humility is defined as taking inventory of one's own values, biases, and perspectives from one's personal life and professional training, increasing awareness and understanding of others' experiences, and examining and minimizing power imbalances (Yeager & Bauer-Wu, 2013). A foundation in cultural humility can help foster better communication, help researchers more deeply understand the context of the study community, help promote relationships of mutual respect, and allow the team to work towards their mutual goal of health equity.

Human-Centered Design

Originating outside of academics, design methodologies, including human-centered design, have been increasingly incorporated into public health-oriented research. Design methodologies have typically been employed in the commercial sector and are broad, consisting of approaches, such as design thinking, co-design, human-centered design, among others. Similar to CBPR, these design methodologies include a strong emphasis on participation and engagement, including individuals who are the target of the service or product throughout the design process from design to testing and refining solutions.

Human-centered design has in part originated from design thinking and, at times, the terms have been used interchangeably. Design thinking began in the 1980s and was popularized in the 1990s as an approach to foster innovation in technology and business through the creation of consumer-driven products and services and is now increasingly used within healthcare and research (Brown & Wyatt 2010; Suen et al., 2010). Broadly, human-centered design is a process that incorporates alternating divergent and convergent thinking through activities that attempt to capture the advantages of approaching challenges and solutions through a human-focused point of view while balancing real-world limitations (e.g., finances, time, etc. Chen et al., 2020). Like CBPR, the overarching goal is to develop solutions that are meaningful, feasible, effective, and, ultimately, address problems that are of high-priority for the involved individuals. Chen et al.'s review of CBPR and human-centered design identified key similarities between the two approaches and includes a focus on co-creation, the participation of partners throughout all stages of the process, bidirectional transfer of knowledge, along with guiding principles of flexibility, generalizability, systematic, and iteration (Chen et al., 2020).

The process of human-centered design generally involves three phases, inspiration, ideation, and implementation (Brown & Wyatt, 2010). While intended to be a flexible process that is not necessarily linear, the inspiration phase is generally the starting point and includes activities that work to frame, research, and synthesize the research team's understanding

of an identified problem (Brown & Wyatt, 2010; Suen et al., 2021). The inspiration phase seeks to develop a deep understanding of the identified problem from the perspective of key stakeholders and in the process develop empathy and learn about barriers and workarounds (Brown & Wyatt, 2010; Chen et al., 2020) without a focus on developing a solution. Next, the ideation phase seeks to translate the understanding of the problem garnered in the inspiration phase into possible solutions using multiple approaches to brainstorming (Brown & Wyatt, 2010; Suen et al., 2021). Possible solutions are then rapidly prototyped to create a tangible representation of the solution that can be a low-risk way to check assumptions, gauge responses from key stakeholders, and uncover potential implementation challenges early (Suen et al., 2021). The implementation phase focuses on the testing and prototyping of multiple potential solutions in a systematic and iterative fashion (Suen et al., 2021; Chen et al., 2020). Throughout these phases, the exact methods can vary but often incorporate qualitative methodology, such as structured observations, semi-structured interviews, and focus groups and include activities designed to foster empathy, examine problems from multiple perspectives, and generate novel ideas.

While human-centered design offers a methodology and orientation that aligns well with the guiding principles of CBPR, important differences exist between the two and potential points of tension as well. Chen et al.'s review also identified differences between human-centered design and CBPR, namely differences in values, outcomes, and process (Chen et al., 2020). For example, human-centered design is typically a limited, time-bound engagement with stakeholders rather than a long-term commitment between research teams and communities (Chen et al., 2020). While participatory in nature, human-centered design does not recognize or emphasize power differentials between research teams and communities and the intentionality CBPR takes in shifting power to communities is not necessarily a component of human-centered design (Chen et al., 2020). While such differences need to be recognized, human-centered design represents a methodology that can complement CBPR and serve as an additional tool in developing potential solutions that center communities' needs and priorities while working to advance equity.

Frameworks in Participatory Research

For investigators new to a CBPR approach, one potential question may be in identifying an appropriate theoretical and/or evaluation framework for their research. Below we introduce multiple frameworks that have been used in CBPR studies, including in auditory research. We also introduce the CBPR Conceptual Model (Wallerstein et al., 2008, 2018), a framework used to evaluate and reflect on community-academic partnership processes within CBPR. See Table 2 for a summary of selected frameworks.

Theoretical Frameworks

Theoretical frameworks can help to explain the variables that influence outcomes, and can help provide better understanding of the research question by connecting to existing knowledge. Studies involving CBPR are broad, and have included a variety of different theoretical frameworks, however, critical to the frameworks using CBPR is the consideration of the social determinants of health. As reviewed in this special issue by Bush and

colleagues, social determinants of health are the “conditions in which people are born, grown, work, live, and age”, such as income, education, housing, and access to food (WHO, 2021). Below we describe two theoretical frameworks that have been used in studies that involve a CBPR approach, including within auditory research.

The socio-ecological model (SEM) is a theoretical framework that examines how factors of influence at the individual (e.g., age, education, attitudes, health literacy, behaviors), interpersonal (e.g., friends, family, coworkers), community (e.g., schools, workplaces, neighborhoods, church), institutional (e.g., academic, health care organizations, state and local health departments), and societal levels impact health conditions and health-related behavior (Bronfenbrenner, 1989; McLeroy et al., 1988). The core principle of the SEM is that a person interacts with all levels of their environment, and there is a reciprocal interaction that influences a person and their environment. Numerous CBPR studies have used the SEM as a framework for understanding the multiple factors that impact health at different levels, to identify leverage points for intervention, and to develop approaches for prevention and health promotion (e.g., Mancera et al., 2018). A CBPR approach complements the SEM by integrating community engagement and stakeholder representation from multiple contexts, or levels of environments. In auditory research, Ingram et al. (2016) conducted a CBPR multilevel community needs assessment using the theoretical framework of the SEM in preparation for the Oyendo Bien (Hearing Wellness) clinical trial (clinicaltrials.gov identifier: NCT03255161). The starting point for this work was co-learning from a multi-level community needs assessment. Established academic/community partnerships identified and allowed access to a range of relevant stakeholders for the qualitative needs assessment, including interviews and focus groups (Ingram et al., 2016). CBPR partners co-designed the needs assessment to gain insights from older adult patients with hearing loss, family members, Community Health Workers, physicians, and other community members, thus addressing all levels of the Socioecological Model. Outcomes revealed the needs and strengths of the community to address hearing loss and ongoing health disparities (Ingram et al., 2016).

The Health Services Utilization (HSU) model is a theoretical framework for studying the factors that contribute to an individual’s use of healthcare services (Aday & Andersen, 1974; Andersen & Newman, 1973; Andersen, 1995). According to the HSU model, healthcare use is determined by the interaction between individual and contextual predisposing factors (e.g., age, race/ethnicity, gender, health beliefs, the demographic makeup of communities, and societal norms), enabling factors (e.g., health insurance, health policies in place, financial equity, availability of community supports), and need (perceived and evaluated individual and community health indices). A multitude of systematic reviews, retrospective chart reviews, and prospective research studies have used the HSU model as a framework to understand correlates of behaviors moderating healthcare usage, and to help contextualize results (see also review by Babitsch, Gohl, & von Lengerke, 2012). Using a CBPR approach can help provide context and guidance on variable selection and interpretation of findings within the HSU model (e.g., Podder et al., 2021). Within auditory research, the Conexiones (Connections) randomized controlled trial used the HSU model with a CBPR approach to evaluate the feasibility of Community Health Workers as patient-site facilitators in

teleaudiology service delivery (Coco, 2021), discussed below in the section “Examples of Community-Based Participatory Research”.

Evaluation Frameworks

Evaluation frameworks provide a structure to measure the extent to which a program or intervention has achieved the projected outcomes or goals. They may focus on the measurement of impact, outcome goals, and/or cost/benefit. This guiding framework may be particularly advantageous in auditory research, which can lack consistent reporting, limiting the ability to compare across studies (Perez & Edmonds, 2012). Below, we provide an overview of two evaluation frameworks that may be applied to CBPR.

The PRECEDE-PROCEED model is a structure for planning, implementing, and evaluating health promotion interventions and programs (Green, 1974; Gielen et al., 2008; Freire & Runyan, 2006). PRECEDE-PROCEED is an acronym for Predisposing, Reinforcing and Enabling Constructs in Educational Diagnosis and Evaluation-Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development. The framework is undertaken in two distinct steps. First, the PRECEDE phase includes a thorough needs assessment of problems and needs in a given population, such as through a forum or focus group, as well as setting priorities and identifying administrative and policy-related issues that can influence what can be implemented. Next, the PROCEED phase involves implementing the intervention, conducting a process evaluation, and evaluating impact. In CBPR, the PRECEDE-PROCEED model can help provide structure for identifying community knowledge, capacity, and readiness around an intervention (e.g., Bammann et al., 2021). An example of the use of the PRECEDE-PROCEED model in the auditory literature is described in Carson and Pichora-Fuller (1997). The authors used a participatory approach for program planning to improve communication for seniors with hearing loss in a residential facility in Vancouver, British Columbia. The authors emphasized that the PRECEDE-PROCEED model is appropriate for program implementation and evaluation in the area of audiologic rehabilitation because it emphasizes an ecological approach that is community-based and addresses real-life concerns, and therefore results in program objectives that are more realistic to the target community or individual’s lives (Carson & Pichora-Fuller, 1997).

The RE-AIM evaluation framework provides researchers with a specific and standardized guide for evaluating and reporting the feasibility and impact of public health interventions (Glasgow, Vogt, & Boles, 1999). The RE-AIM acronym stands for Reach (participation rate and characteristics of individuals who are willing to participate in the intervention), Effectiveness (impacts of the intervention on outcomes of interest), Adoption (the factors influencing participants’ adoption of the intervention), Implementation (the extent to which the intervention is delivered consistently), and Maintenance (the extent to which an intervention becomes institutionalized or part of routine practice). The RE-AIM framework has been employed in numerous behavior change and health promotion interventions to measure various health issues and intervention targets (Glasgow et al., 2019). RE-AIM helps guide consistent reporting of findings, helping to improve external validity and translation of research to practice. In CBPR, RE-AIM helps provide structure to evaluate community and

organization-level capacity, feasibility, and readiness (e.g., Tapp et al., 2014). Furthermore, there are opportunities to integrate elements of human-centered design into the RE-AIM framework (Chen et al., 2020). In an auditory research context, the Conexiones RCT used elements of RE-AIM to evaluate the extent to which the novel service delivery model under study was feasible (Coco, 2021). RE-AIM complements CBPR because it provides a framework for sustainability, and can facilitate transparent communication and reporting of each stakeholder's priorities, roles, and responsibilities.

CBPR Conceptual Model

In addition to these theoretical and evaluation frameworks, CBPR itself can be the focus of study. A conceptual model for CBPR was developed by Wallerstein and colleagues (2008, 2018). In this conceptual model, the major constructs include the contexts, partnership processes, intervention and research processes, outputs, as well as major outcomes and how each of these areas feeds back into the others. This CBPR conceptual model may be of growing relevance and importance as more auditory researchers adopt a CBPR approach in the future.

Applications Within Auditory Research

An Ecological Approach Within Auditory Research

Taking an ecological approach to the study of hearing loss may already be familiar to some auditory researchers. An ecological and multi-dimensional view of hearing loss has been described in the auditory literature related to applying the World Health Organization International Classification of Functioning, Disability, and Health (WHO, 2001) to hearing as the health condition of interest (Meyer et al., 2016; Granberg et al., 2014; Danermark et al., 2013). Contextual factors within the WHO-ICF, such as social, language, and cultural factors, that influence lived experience of hearing loss as well as access to hearing healthcare services, can be studied with a CBPR approach. The role of an "auditory ecology" has been described by Gatehouse et al. (2003) and later expanded upon by Noble (2008) as the types of environments in which listeners must function and the interaction of these environments with the personal characteristics of the individual, their auditory abilities, and the amplification that they have access to from amplification technology such as a hearing aid. Likewise, within research and clinical practice related to rehabilitative audiology, the social context of a person's lived experience with hearing loss is considered essential in taking a patient-centered and/or family-centered approach to comprehensive care (Grenness et al., 2016).

Examples of Community-Based Participatory Research

There is a recent history of the use of CBPR within auditory research. A CBPR-based National Center for Deaf Health Research was established in 2005 following the work of the Deaf Health Task Force in 2003. The history of the University of Rochester Prevention Research Center is detailed in a publication by McKee et al. (2012) about engaging the Deaf community in Rochester, New York to conduct health research. This included studies such as the major Deaf Healthcare Survey, which was an American Sign Language linguistic and cultural translation of the Behavioral Risk Factor Surveillance Survey, a public health

survey conducted by the Centers for Disease Control in all 50 states (Graybill et al., 2010). The key benefits of their use of a CBPR approach are outlined by McKeee et al. (2012) including advancing an understanding of cultural and linguistic differences often held between researchers and the Deaf community using American Sign Language. An emphasis on maintaining cultural competency and cultural humility by the study researchers was described.

The Oyendo Bien clinical trial (clinicaltrials.gov identifier NCT03255161) is a CBPR study that involves community partnership and interdisciplinary collaboration, including with trained local Community Health Workers, audiologists, and public health researchers from the Arizona Prevention Research Center. Community partners are equal members of the research team, and are engaged at all levels of the research process, including a rigorous needs assessment framed within the socioecological model, study design, recruitment, intervention development and implementation of a randomized controlled trial, and dissemination of results. The intervention is a five-week Community Health Worker-facilitated hearing health education program focused on improving communication for Spanish-speaking older adults with hearing loss in Southern Arizona (Marrone et al., 2017). A CBPR approach was undertaken for the co-development of the intervention with community partners. Building upon needs assessment findings (Ingram et al., 2016), trainings for Community Health Workers were co-developed with audiologists and other members of the CBPR team. The outcomes of this iterative process were trainings to build awareness among Community Health Workers around hearing loss and community resources, as well as a series of more in-depth trainings on how to facilitate a hearing health education and support group. These trainings were co-developed by and for Community Health Workers with relevant prior work experience with leading health promotion groups for management of chronic health conditions with older adults (Sánchez et al. 2017). The CBPR team then co-developed and iteratively revised a pilot intervention, Oyendo Bien (Marrone et al., 2017). This collaborative process differed from other traditional research methods in which the researcher would revise the materials in a top-down approach. Instead, by taking a CBPR approach to the development of the Oyendo Bien program, the priorities and strengths of the community could be emphasized through the participatory engagement of community partners in the intervention development. Results of the Oyendo Bien 5-week Spanish-language hearing health education pilot study showed that, following the program, participants increased self-efficacy and decreased stigma around hearing loss (Marrone et al., 2017).

The Conexiones clinical trial (clinicaltrials.gov identifier NCT03864003) builds off of CBPR community partnerships from the Oyendo Bien project team. This study first evaluated the feasibility of multilevel trainings for Community Health Workers as patient-site facilitators in teleaudiology-delivered hearing aid services for Spanish-speaking older adults with hearing loss in a US/Mexico border community in Southern Arizona (Coco et al., 2021). As a CBPR study, community partners, including Community Health Workers, collaborated with researchers on developing study design and outcomes measure selection, recruitment, and dissemination of findings. The results of this study indicated that teleaudiology-delivered hearing aid services with Community Health Workers as trained local facilitators is a feasible service delivery model, as indicated by positive patient

satisfaction, improved communication self-efficacy from pre-fitting baseline, and other hearing-related outcomes (Coco et al., submitted). Importantly, while the researchers were not from the community, they recognized that collaboration with local health staff was crucial for the project's success. Further, a CBPR approach helped deepen partnerships in the community, built capacity through grant funding and trainings, and generated community-level awareness on the topic of hearing health. In addition, a CBPR approach helped ensure that the study question was relevant, and that the measurement tools were culturally appropriate and acceptable, thus improving the validity of study results.

Example of Human-Centered Design

The HEARS (Hearing health Equity through Accessible Research and Solutions) intervention is another community-engaged study that incorporates a Community Health Worker-partnered model to hearing care, specifically partnering with older adult peer mentors (clinicaltrials.gov identifier: NCT03442296). Peer mentors deliver a structured hearing care program that includes fitting and orientation of an over-the-counter amplification device and targeted aural rehabilitation with indirect supervision by a team of audiologists (Suen et al., 2021). Throughout the development and piloting of the HEARS intervention as well as the execution of a larger-scale randomized controlled efficacy trial, human-centered design practitioners have worked as consultants as well as embedded within the research team to aid in infusing human-centered design throughout the research process. From the development of training program for Community Health Workers delivering the HEARS intervention to the development of recruitment strategies, human-centered design was employed, including dedicated observations, brainstorming sessions, and prototyping activities with peer mentors and community partners (Suen et al., 2021).

Additional Participatory Studies With Community Engagement

Hearing Norton Sound is a clinical trial involving CBPR to improve access to hearing screenings for the pediatric population (clinicaltrials.gov identifier NCT03309553). In this study, researchers evaluated a novel service delivery model in Alaska, US involving telemedicine referrals for hearing loss and middle ear disease for children in rural public schools (Kleindienst Robler, Inglis, et al., 2020). The researchers elicited feedback on study design from an Alaska Stakeholder team, which included educators, Alaska Native parents, public health researchers, audiologists, otolaryngologists, and administrators.

iManage (My Hearing Loss) is an internet-delivered intervention for individuals with hearing loss developed using a participatory design approach. Stakeholders, including eHealth experts, individuals with hearing loss, audiologists, and other experts reviewed the conceptual design, participated in focus groups to provide feedback on content, evaluate a mock-up prototype, and review program content for future a usability evaluation (Burden et al., 2020). Through this thorough process, the concept of the iManage tool shifted from its original focus on self-management to decision coaching on seeking care for hearing loss.

Advantages and Challenges of Conducting CBPR

One advantage of CBPR is that it makes possible studies that would otherwise be impossible without community partnerships. Also, a benefit of a CBPR approach is the synergy

of partnerships, combining expertise across the team with community partners bringing a knowledge and understanding of community strengths, and research partners bringing subject matter expertise. Another advantage of CBPR is its focus on advancing equity and social justice. Further, involving the community in the research process leads to more relevant research questions and acceptable study designs, leading to potentially more valid results.

There are also a number of potential difficulties that CBPR teams need to work together to address. For example, CBPR often requires greater human and financial resources, and more time to develop and maintain relationships, as compared to traditional research. However, a greater number of funding agencies are recognizing this challenge and supporting greater resource allocation to community partners. An important area for researchers embarking on CBPR are the ethics involved in community/academic partnerships, including addressing the researchers' cultural and historical context of identity within the community, as well as decision-making power and ownership of results (Hoover et al., 2019). In addition to these potential challenges, several limitations common among CBPR studies have been cited in the literature and were summarized by Faridi et al. (2007). First, there has been criticism of a lack of common terminology across studies and non-standardization of reporting, limiting a global understanding of the CBPR elements undertaken in each study's context. As an antidote to this, a reporting guideline checklist was developed to help researchers when writing about CBPR studies (Smith, Rosenzweig, & Schmidt 2010). Another critique has been that there is a wide range of degree of community participation across different CBPR research studies, with few studies attaining the ideal fully community-driven research. This issue may be addressed moving forward through greater description in reporting on ways in which the community is involved throughout the research process. Finally, some CBPR studies are criticized for their limited generalizability. However, this reflects the tension between adequate external validity for specific communities or cultural groups for whom the generalizability of traditional laboratory-based and clinical research can similarly be limited and criticized for lack of adequate representation and cultural responsiveness.

Limitations and Future Directions

The purpose of this article was to introduce auditory researchers to CBPR. A limitation of our article is that we did not conduct a systematic review, and thus the studies presented may not fully represent the full breadth of literature on this topic. In the future, as CBPR has greater uptake in hearing healthcare, likely systematic reviews will be warranted. Also, readers of this article are encouraged to continue learning about CBPR and build relationships with community partners and researchers with experience in CBPR. Our intention is not to imply that CBPR in the area of auditory research can be conducted on the basis of reading this single article, but it could serve as a starting point and a catalyst to developing interest. Future directions include a call for increasing CBPR and human-centered design within the field of auditory science to address health equity, and for all researchers to reflect on broader questions of equity in research.

Advancing Equity And Inclusion In Hearing Healthcare Research

Recently, Ellis et al. (2020) raised CBPR as an anti-racist research practice for Communication Sciences and Disorders (CSD). In what is likely to become a seminal article for our field, they review ways in which systemic racism disadvantages and is a burden on the lives of Black, Indigenous, and People of Color (BIPOC) populations. Ellis et al. observe that while research holds minimization of bias as a central tenet, health disparities are persistent. How can this be? The authors stress that it is critical for researchers to acknowledge the problem of the lack of diversity and inclusion within the research workforce and research participant samples within CSD. They implore their readers to acknowledge that the majority of research in the field of CSD has been developed by white scientific investigators with mainly white research participants.

Within auditory research specifically, Pittman et al. (2021) conducted a systematic review of clinical trials of hearing loss interventions for adults and documented the very limited representation of racial and ethnic minority individuals within auditory research and the limited reporting of these data at all. Surprisingly, only five prior clinical trials in the U.S. between 1990–2020 of the over 125 trials reviewed (those focused on adults and published before 2020) had adequate representation of racial and ethnic minorities (defined as >30% non-white representation). Additionally, only 12.7% of the studies even reported on the race/ethnicity of the participant samples. Certainly much greater work in this area is warranted for auditory research.

Urgently, Ellis et al. (2020) explain that a critical component of anti-racist research is to adequately involve the community in the research process through equitable collaborative partnerships and taking an alternative approach to research such as CBPR. They explain that different research questions can be asked when informed by community involvement and the power dynamics in research can be explicitly reflected upon. Researchers must adopt humility in the research process to ensure reflection and action on the potential influences of systemic racism, power, privilege, and implicit bias. Only then will there be adequate representation, inclusion, equity, diversity and access to innovation and the knowledge generated by research. To this point, the current authors acknowledge the privilege that it is to be able to conduct scholarship in the area of CBPR to advance hearing health equity. Collectively, the work of Ellis et al. joins with the work of others outside the field in presenting important insights into how CBPR can help to reduce health disparities (e.g., Wallerstein & Duran, 2006). Ward et al. (2018) explain that equity within a CBPR approach is characterized by resource-sharing, immediate benefit to the community, transparency, participation in meetings, and influence in decisions within the time period of the study itself, as well as long-term impacts leading to social change. We encourage investigators to reflect on power dynamics, positionality, and level of community engagement within the research process to move towards equity in research beyond considerations of representation or recruitment and retention alone.

Conclusion

The goal of this article was to introduce CBPR to auditory scientists and those interested in health disparities research. The CBPR approach is contrasted with a traditional research approach, which may only engage community members as passive participants within the research study. Alternatively, CBPR fits within the continuum of community engagement in research along the end with high community involvement throughout the research process. An understanding of the eight key principles of CBPR begin to illuminate how and why CBPR is important to advance health equity. With a focus on health equity, CBPR and human-centered design in the context of hearing healthcare will play a part in advancing inclusion, diversity, and equity through increased access to innovation, respect and value of community wisdom, and making research contributions with high relevance to the community. Given the importance of diverse perspectives representing greater inclusion of people of color and multicultural populations, hearing healthcare research could benefit from wider adoption of a CBPR approach and human-centered design principles to advance health equity and anti-racist research practices.

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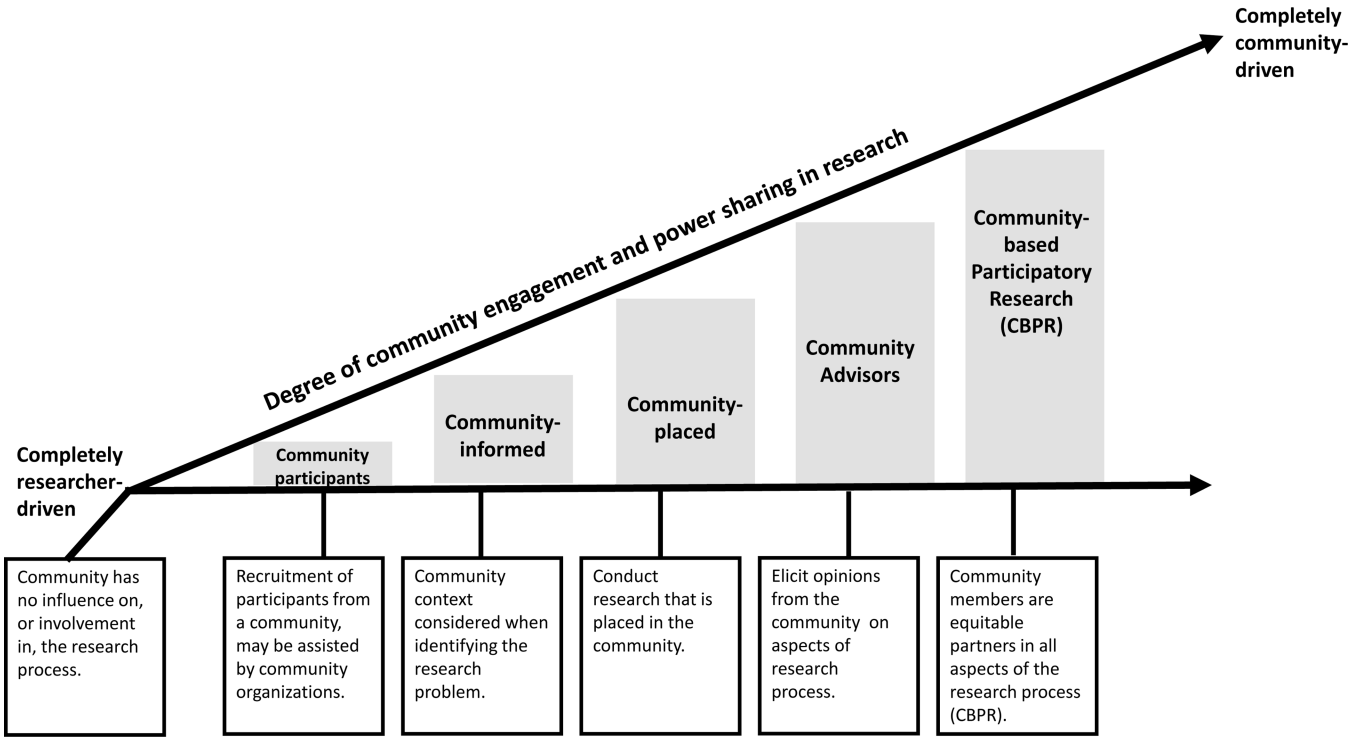

Figure 1.
Comparisons between traditional research and CBPR across the research process.

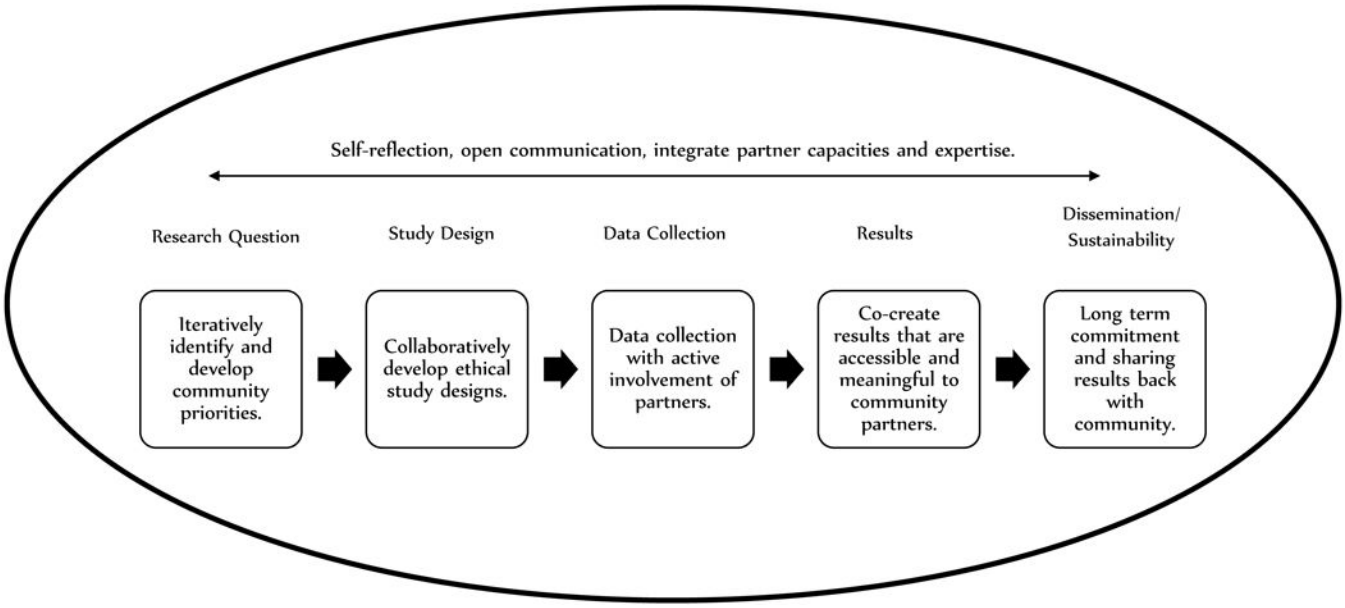

Figure 2.

Methodological approaches to establishing longstanding successful CBPR partnerships (see: Examining Community-Institutional Partnerships for Prevention Research Group, 2006; Shalowitz et al., 2009.; Coombe et al., 2020.)

Table 1.

Comparisons between traditional research and Community-Based Participatory Research across the research process (adapted from Horowitz, Robinson, & Seifer, 2009).

Stage of Research	Traditional Auditory Laboratory or Clinical Research	Community Based Participatory Research
Identify research problem	Individuals, a community or population as a passive subject of study.	Community partners involved as equal members of the research team, recognized and respected in the research process including to set the research agenda.
Study design and implementation (data collection, analysis, interpretation)	Based on what is known in scientific literature.	Collaboration with the community, based on an understanding of local values and challenges in combination with the science.
	Researchers gain skills and knowledge.	Build on strengths in the community and addresses challenges to help build community capacity as well as researcher capacity.
	Typically lacking participation from the community.	Decisions are reviewed iteratively, taking time for feedback from Community-Based Participatory Research members.
Dissemination of findings	Researchers control data and decide how and where to share findings.	Researchers and community partners decide together how to disseminate including peer-reviewed publications as well as communication to community-relevant audiences.

Table 2.

Examples of evaluation and theoretical frameworks that have been used in participatory research

Framework	Brief description	Potential Complement with CBPR
Evaluation Frameworks		
PRECEDE-PROCEED: Predisposing, Reinforcing & Enabling Constructs in Educational Diagnosis & Evaluation-Policy, Regulatory, & Organizational Constructs in Educational & Environmental Development (Green, 1974; Gielen et al., 2008; Freire & Runyan, 2006)	Framework for assessing community needs for planning & evaluating a health promotion program.	Can help identify community knowledge, capacity, & readiness around an intervention.
RE-AIM: Reach, Effectiveness, Adoption, Implementation, Maintenance (Glasgow, Vogt, & Boles, 1999)	Framework for planning, evaluating, & reporting feasibility & public health impact of interventions.	Can facilitate transparent communication & reporting of stakeholders' priorities, roles, & responsibilities.
Theoretical Frameworks		
HSU: Health Services Utilization (Aday & Andersen, 1974; Andersen & Newman, 1973; Andersen, 1995)	A conceptual model for understanding the factors that contribute to healthcare use. Healthcare use is determined by the interaction between individual & contextual predisposing factors enabling factors & need.	CBPR partners can be engaged to determine the HSU factors under study.
SEM: Socio-Ecological Model (Bronfenbrenner, 1989; McLeroy et al., 1988)	A model to understand the multiple factors that influence health. Influence is at the individual, interpersonal, community, institutional, & societal levels.	The SEM integrates community engagement / stakeholder representation from multiple levels.