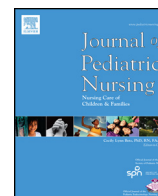




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East African Perceptions of Barriers/Facilitators for Pediatric Clinical Research Participation and Development of the Inclusive Research Model

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ABSTRACT

Purpose: This study sought to gain a greater understanding of perceptions related to barriers/facilitators for pediatric (ages 0–17) clinical research participation among East African immigrant community members.

Design and Methods: Community leader interviews ($n = 6$) and focus groups with lay members ($n = 16$) from the three largest East African communities in the Seattle area (Eritrean, Ethiopian and Somali) were conducted. Discussions were semi-structured based on existing barrier/facilitator research and analyzed using directed content analysis to identify major themes.

Results: Analysis revealed two novel barrier sub-themes: inadequate interpretation and translation of information even when services were available and a lack of adequate vocabulary in preferred languages. Participants also confirmed previously identified logistical barriers/facilitators (lack of knowledge regarding clinical research; time, cost, transportation, and child care challenges; providing incentives) and psychosocial barriers/facilitators (mistrust of research; cultural and/or religious differences; connecting benefits to the community; involving religious/community leaders or organizations and including community members on the research team; transparency in the research process; presenting results to the community) for clinical research participation among underrepresented groups.

Conclusion: Perceptions of barriers/facilitators for pediatric clinical research participation among East African immigrants identified two novel sub-themes and confirmed those previously described by other underrepresented communities.

Practice Implications: To facilitate more inclusive research participation, researchers, nurses and other health care providers might consider ensuring adequate time for discussion of the research study and process, engaging the community in the research process, employing lay reviews of translated materials and/or oral consent processes, and other strategies outlined in the Inclusive Research Model.

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Introduction

African immigrants are one of the fastest-growing populations in the United States (U.S.) totaling 2.1 million as of 2015, with the majority originating from West (36.3%) and East (28.9%) Africa (Anderson, 2017; Capps, McCabe, & Fix, 2012; Gamino, Trevelyan, & Fitzwater, 2014). Despite evidence showing disproportionately high rates of some diseases affecting this population, such as type 1 diabetes and autism in East African youth, African immigrants are significantly underrepresented in clinical research (Adekeye, Adesuyi, & Takon, 2017; Buseh, Kelber, Millon-Underwood, Stevens, & Townsend, 2014; Buseh, Stevens, Millon-Underwood, Kelber, & Townsend, 2017; Buseh, Underwood, Stevens, Townsend, & Kelber, 2013; Hewitt et al., 2016;

Hurtado-de-Mendoza et al., 2014; O'Connor, Dobra, Voss, Pihoker, & Doorenbos, 2016). Underrepresentation in clinical research is problematic because it can exacerbate existing health disparities and inequities since scientific advances may not apply to those not in the evidence base and may also decrease access to potentially life-saving or life-prolonging therapies (Chen, Lara, Dang, Paterniti, & Kelly, 2014).

Barriers to clinical research participation among African immigrants in general have been described in a handful of studies and include a deep mistrust of researchers due to recent historical mistreatment by Western researchers in Africa (i.e. vaccine and HIV trials), community leaders who act as gatekeepers to protect their members, concern that discoveries specific to African populations may lead to discrimination, and cultural beliefs that the body should be left as whole and that one's health is in God's hands (Buseh et al., 2013; Buseh et al., 2014; Buseh et al., 2017). Facilitators include acknowledgement of past exploitations by researchers, the use of recruiters from the African community, getting to know researchers personally, a sense of transparency

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and involvement in the research process, a desire to help their community, receiving culturally relevant education about the research process and area of study, and a benefit-sharing plan if a profit might be made (Buseh et al., 2013; Buseh et al., 2014; Buseh et al., 2017). Additional barriers broadly affecting underrepresented populations in research (e.g. children, racial and ethnic minorities, and those with limited English proficiency, lower levels of education and income, and/or who live in rural areas) include cost, time, transportation, lack of availability of interpretation services/translated materials, poor communication, perceived harm, and not receiving research study results (Pinto, McKay, & Escobar, 2008; Aristizabal et al., 2015; Braunstein, Sherber, Schulman, Ding, & Powe, 2008; De las Nueces, Hacker, DiGirolamo, & Hicks, 2012; Ford et al., 2008; George, Duran, & Norris, 2014; Mills et al., 2006; Salman, Nguyen, Lee, & Cooksey-James, 2016; Schmotzer, 2012; UyBico, Pavel, & Gross, 2007).

While limited previous work has described barriers and facilitators to clinical research participation among African immigrants and underrepresented populations in general, it is not known whether these factors also apply to pediatric participation in East African immigrant communities. Recent research has shown that East African immigrant youth with type 1 diabetes are underrepresented in on-going low-risk diabetes studies in youth. For example, a national longitudinal study of diabetes affecting youth study included 22 African immigrant youth with type 1 diabetes across six study sites, yet evidence shows that there are at least 60 East African immigrant youth with type 1 diabetes at just one of the study's sites during a similar timeframe (Jaacks et al., 2012; O'Connor et al., 2016). This underrepresentation in research serves as a barrier to understanding how type 1 diabetes affects a specific and vulnerable populations such as East African immigrant youth. The present study sought to gain a greater understanding of East African immigrant participation in pediatric clinical research by exploring and describing perceptions among health care workers and lay members of three East African communities in the Seattle area. Results from this qualitative study will help guide health researchers, nurses, and other health care professionals towards practices that will better serve East African communities in the future.

Design and Methods

Study Design

This descriptive qualitative study using directed content analysis (Hsieh & Shannon, 2005) explored and described the perceptions of barriers/facilitators for pediatric clinical research participation among the East African community through individual interviews and focus groups. Descriptive qualitative research studies are not rooted in any particular discipline or philosophical approach and often use content analysis to categorize and synthesize themes derived from textual data (e.g. interview transcripts, observation and field notes) to characterize phenomena of interest and identify important contextual features (e.g., barriers and facilitators to research participation; Polit & Beck, 2018; Sandelowski, 2000). Directed content analysis is one approach to descriptive qualitative research that begins inquiry with the goal of adding to extant knowledge by probing for details in a different context. The work relies on previous research to inform the current analysis (e.g. using previous themes as interview questions to confirm prior findings and explore additional responses; Hsieh & Shannon, 2005).

Participants and Setting

While we were specifically interested in barriers/facilitators related to pediatric clinical research participation, we chose to include only adult participants because parents/legal guardians must provide their consent for youth to participate in clinical research and are the ultimate decision-maker regarding research participation. Thus, this study explored the perceptions of adult members of the East African community

regarding barriers and motivators for the participation of East African youth (0–17 years of age) in clinical research. The study included community leader interviews ($n = 6$; 2 Eritrean, 2 Ethiopian, 2 Somali) and three focus groups with lay community members ($n = 16$; 5 Eritrean, 5 Ethiopian, 6 Somali) from each of three largest East African populations in the metropolitan area. Participants were age 18 and older and born in either Eritrea, Ethiopia, Kenya, or Somalia. We chose to include community leaders due to their in-depth knowledge of both health care and the East African community and to include lay community members to allow us to check that the community leaders did not hold substantially different views compared to the rest of the community based on their knowledge of health and health care (member-checking).

Sample sizes for the interviews and focus groups were chosen based on consultation with an expert in qualitative research design in an effort to achieve data saturation (author HS). Purposive sampling was used to identify community leaders in an effort to maximize the ability to yield insights and themes within and across these different communities. Community leaders worked for health-related organizations that served the community and were identified through existing relationships between community members and the research team. Snowball sampling using community leaders and research team contacts was employed to identify lay community members who did not have any substantial connection to or knowledge of the health care industry and who were parents of children <18 living at home.

Data Collection

Data were collected through six individual leader interviews and three lay focus groups conducted in the community between July and December 2014. Demographic information was limited to place of birth, length of time in the U.S., verified type of employment (to ensure community leaders were in health-related roles and lay members were not), and confirmation of children's ages, to ensure a sense of privacy. Community leader interviews were conducted first and barrier/motivator themes were identified prior to conducting the three focus groups of lay community members to allow for member-checking. Additionally, we chose to conduct the focus groups with each of the three largest East African communities separately to explore whether differences in perceptions existed between these communities.

All interviews and focus groups were conducted in community locations (community leader workplaces, East African community organization offices, and an East African restaurant), were audio-recorded, professionally transcribed with identifying information removed, and were conducted in English due to significant budgetary constraints. The project did not have sufficient resources to interpret interviews and then translate interview transcripts into English and then translate back into the original language to ensure accuracy (back translation), the standard process used for translations. To address this resource limitation, we: 1) recruited a Somali community member to the research team who conducted the interviews and analysis, 2) interviewed community leaders who work with LEP community members, and 3) compared responses from community leaders and lay community members for shared perspectives. A waiver of consent was obtained from the University of Washington Institutional Review Board, although researchers chose to obtain consent from all participants prior to each interview or focus group in an effort to maximize transparency. Participants were given a \$25 gift card and food was provided during the focus groups.

Each interview/focus group was led by the second author, who is from Somalia and trained in conducting interviews and moderating focus groups. The first author was also present and took notes during the interviews and focus groups. The moderator used a discussion guide, asking questions verbatim and in the same order (general to specific) for each interview and focus group to ensure consistency and facilitate transition from the introduction to the key study questions. Semi-structured discussions began with open-ended questions followed by specific probes based on existing barrier/facilitator research for each

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