Enhancing Hispanic Community Engagement in AT Research

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INTRODUCTION

Research has well-established that assistive technologies (AT) allow individuals with disabilities to increase their function, safety, and participation in daily life activities. However, a third of AT devices are abandoned resulting in considerable health care costs, increased burden on caregivers, and decreased independence, quality of life, and safety for device users [1]. Given the positive impact of stakeholder engagement in research, there is a call in rehabilitation research for greater involvement of stakeholders and communities in the research process [3]. Community engagement in AT research can help create a better match between what users want and need and the available AT. It can do it by identifying more relevant questions, enlisting community resources, and generating knowledge that is more easily transferable and usable by the users of AT [2]. However, there are many challenges in translating community engagement principles into community-based AT research in low-income Hispanic communities. They include: 1) lack of AT researchers' understanding and experience with engaging communities; 2) skepticism about research in theses communities; 3) power differences in which the research process is still mainly controlled by the researchers, and; 4) a limited group of stakeholders being involved in rehabilitation research [4,5]. The AT field is lacking richly descriptive information about community engagement in research, with practical, real-world examples and application of principles of engagement principles.

This paper describes an approach to community engagement from an NIH-funded study of disparities in the adoption and use of AT by older Hispanics. We aimed to identify effective practices to enhance community engagement of low-income Hispanic communities in AT research. The results of this research may be used to significantly improve the effectiveness of AT researchers' efforts to engage marginalized low-income communities in their studies.

METHODS

Design
This is an ongoing mixed-methods study which started on August 1, 2019 to identify the functional disabilities of 250 Hispanic older adults and the gender differences in the factors influencing the use of AT. We have successfully recruited 149 participants as a result of employing the following community engagement procedures and activities throughout the research process: 1) during the Planning the Study Phase we conducted working groups meetings with stakeholders to co-create the funding proposal for the study in its early stages to assure the relevance of the research question and study procedures, as well as obtained and incorporated their input to address reviewers' critiques in preparing a resubmission of the application; 2) during the Conducting the Study Phase (once the study was approved), we convened a Community Advisory Board (CAB) to revise recruitment and data collection materials, provide guidance on how to overcome implementation challenges, participate in recruitment and data collection, and participate in data analysis; 3) during the Disseminating the Study Results Phase, we obtained and incorporated CAB input to identify partner organizations for dissemination and develop plans for continually engaging community partners in the progress of the research. The following community stakeholders in Puerto Rico participated in the study: the *G-8, Inc.* (Group of the eight communities of the Caño Martín Peña [CMP]); the *Proyecto Enlace* of the *CMP*; the *CMP* Community Land Trust; the HealthproMed community health clinic; the Puerto Rico Assistive Technology Program at the Medical Sciences Campus; three older Hispanics with functional disabilities residents and residents of the *CMP*; and five community interviewers. We used the following community engagement procedures and activities throughout the research process.

RESULTS

The important ingredients to the success of engaging community stakeholders in our AT study with Hispanic communities were: (1) *early and continuous input*; (2) *building trusting and warm relationships through personal*

connections; (3) *establishing and maintaining presence in the community*; (4) *power sharing*; (5) *shared language*; (6) *ongoing mentorship and support to community members*; and (7) *adapting to the changing needs of the community*.

Early and continuous input. It was crucial to engage community stakeholders' input early in the research process. Community input enhanced the relevance and success of our study in several ways. For example, during the planning phase, the stakeholders validated the significance of the study aims for addressing the disability disparities of the older Hispanics living in this community. They participated in the recruitment and data analysis of the implementation of the preliminary pilot study, and provided valuable input that strengthened the significance and recruitment methods for addressing the reviewers' critiques in the re-submission process. During the conducting the research phase, community input helped alleviate participants' recruitment and implementation challenges, resulting in several modifications to the research protocol. For example, we changed the participants' incentives method from gift cards to cash to accommodate the payment method used by older adults from this community. The CAB recommendation of using the G-8 identification vest during participants' recruitment, assured interviewers and researchers' safe access to the community during recruitment and data collection. During the dissemination phase, the CAB provided valuable input to disseminate the findings of this study in the community's newspaper and in the community health clinic's television through the use of infographics to visually present the results in a more accessible format.

Building trusting and warm relationships through personal connections.
Hispanics have the expectation of building personal connections with their healthcare providers. This personal connection was also expected with the researchers of this study. Therefore, the researchers of this study engaged in close physical contact (such as hugging and kiss on the cheek) with the stakeholders and interviewers to greet them, saying good-bye or acknowledging their outcomes (see Figure 1). We built trust over time by actively listening to community voices, incorporating their voices throughout the research process, and by demonstrating genuine interest in these community stakeholders and interviewers' lives and needs. For example, the research team celebrated the birthdays of the community interviewers, they consistently praised the interviewers' contributions to the study's progress, and monitored and responded to the interviewers' and community stakeholders' needs whenever is possible, such as

Figure 1: Close physical contact between the researchers and community members

connecting community members with disabilities with available AT resources in Puerto Rico, providing transportation support to conduct some of the interviews, or providing supplies to the people affected by Hurricane Maria.

Establishing and maintaining presence in the community. The research team was always visible and engaged in community activities to reflect their commitment of making themselves available to the community, even during the long period of time that the funding agency was reviewing the grant application. Therefore, researchers took time to participate in the community's bingo, annual festival, monthly artisan market, community bike tours and health fairs. They also assured their continuous presence in the community by co-designing a community-based clinical practice course in occupational therapy for older adults of the *CMP* during the summer terms. Having the research team accessible in these community settings increased the frequency and richness of interactions and contributed to the team's commitments to listen and be responsive to stakeholders' concerns.

Power sharing. Power sharing is defined as the actions to balance power, which was essential for establishing a common ground, resolving study implementation challenges, and supporting meaningful engagement, teamwork and collaboration. Researchers employed several actions to balance power, such as dispensing with academic titles (by addressing everyone by their first name), dispensing with formal clothing during the working groups and CAB meetings and during the recruitment process within the community (by dressing with jeans and sneakers). The researchers also encouraged community stakeholders to speak and contribute their ideas, as well as incorporated their ideas and unique expertise throughout the research process. In each meeting, a shared responsibility for decision-making was always adopted. The researchers used body language to show honest interest in stakeholders' input, such as nodding, leaning forward, and making eye contact, as well as paraphrasing their contributions to show understanding (see Figure 2). Finally, we use a circular

Figure 2: Researcher leaning forward, active listening and making eye contact with community members

seating configuration with no head-at-the-table positions during our meetings to demonstrate that the researchers and the community members were equal partners in this study.

Shared language. Shared language in the context of this study refers to the use of a culturally competent communication that increases the understanding between the researchers and the community stakeholders. For this purpose, the researchers employed clear, plain, simple language, free of technical jargon when communicating with the community stakeholders as well in every study's materials for the participants and community members. For example, the stakeholders made changes to improve the clarity of ambiguous statements to community members, such as "persons with disabilities" to a wording more easily understood by the community: "persons with difficulties performing daily living activities." They also recommended keeping the sentences as short as possible and adding bullets to long paragraphs. Changes were also necessary to increase the understandability of AT devices listed in the socio-demographic questionnaire. For example,

Figure 3: Power Point slide with minimum text and visual support for the interviewers' training

"enlarged print documents" was changed to "documents with big letters" and "pill reminders" to "alarms for medications." Lengthy Power-Point presentations during the stakeholders and CAB members, as well as during the interviewers' training that included highly technical language were also edited to keep them as brief as possible. Visual strategies were used to present complex concepts, and to make sure the language and images were clear and easy to understand (see Figure 3).

Ongoing Mentorship and Support to Community Members. Ongoing supervision, mentorship, and support were woven throughout the research process using several strategies. Before going into the field, each community interviewer conducted interviews with another community interviewer as an opportunity to safely practice the entire interview process. Once in the field, the interviewers' first few interviews were conducted with the company of one of the researchers to continue reinforcing the development of interviewing skills and assure data quality. As enrollment progressed, interviewers' research team meetings were held every two months, to foster continual learning, support, and problem-solve implementation challenges. As part of these meetings, data quality and recruitment reports were presented and discussed with the community interviewers to troubleshoot study challenges, such as difficulties in reading the community map to identify the selected houses for the study. Regular one-on-one check-ins with an interviewer and a member of the research staff to debrief, discuss concerns, ensure data quality, and address individual training needs, were regularly held. The use of the WhatsApp Chat Messaging System was also crucial in providing continuous follow-up to the interviewers, informing about the progress of the enrollment process, providing constant motivation to achieve the weekly goals, clarifying interviewers' concerns, and acknowledging the interviewers' achievements. All interviewers recognized the positive impact of the messaging system in supporting their work, as expressed by the following interviewer: "One is more motivated because you (the researchers) give us that encouragement and enthusiasm that is important in the kind of work we are doing." Refresher videos were also sent as needed through the messaging system to revisit pertinent interviewers' skills.

Adapting to the changing needs of the community. Addressing the changing needs of stakeholders and community interviewers facilitated their participation in the research process. For example, to accommodate for child-care challenges, a flexible schedule was implemented to conduct the interviews during the evenings and weekends. Appropriate researchers' outreach at the interviewers' convenient hours through telephone calls or the messaging system was also assured to accommodate for the complex life situations of the community interviewers. Transportation challenges were accommodated as well by conducting all the meetings with the community stakeholders and the interviewers' training within the community venues, such as at the conference room of the *G-8* headquarters or at one of the *CMP* community centers. Finally, research processes that were difficult to implement were also simplified per the interviewers' requests. For example, the researchers modified the community maps by adding the real house number instead of the study's assigned number of the selected houses to eliminate the interviewers' difficulty in identifying the correct houses for this study.

DISCUSSION

Community stakeholders have enormous potential for informing AT research by sharing their expert knowledge and lived experiences, but this is a practice that is often underused by AT researchers. Community stakeholders'

experiential knowledge can improve the quality and relevance of research and enhance research design, implementation, interpretation, and dissemination through the eyes of individuals that represents the study's population of interest. For example, by engaging in a collaborative community-based approach to conduct the AT research, the researchers were able to support the meaningful involvement of the community interviewers, successfully recruit the study's participants, and successfully overcome the implementation challenges.

Some of the principles that emerged from this study reinforce well establish principles of community engagement, including early input, embedding researchers in the community, power sharing, shared language, and ongoing mentorship and support to community members [5-8]. However, a notable finding is the importance of developing a personal relationship between the researchers and Hispanic community members. This points to the need to develop the necessary cultural competence and sensitivity among researchers that target Hispanics populations in their AT research studies, as well as to invest sufficient time to strengthen the partnership with community stakeholders.

CONCLUSIONS

This paper describes our experience engaging Hispanic communities in AT research that can help others develop more effective community engagement in AT studies. This paper also highlights important practices that can help AT researchers develop more effective community engagement studies with Hispanic communities. We believe that these practices can enhance the interaction of researchers and community partners to improve the effectiveness of researchers' efforts to engage marginalized low-income communities in their projects. Future research is needed to test and expand these practices with other minority communities as well as with other approaches of community engagement in AT research.

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