End-of-life Conversations: Report on Nurses' Perspectives about Collaboration in a Community-Based Study

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Article

Abstract

Collaboration is an effective means for nurses to establish professional relationships with organizations, and especially communities. When nurses collaborate on community-based research, they strengthen the ability to identify community level healthcare needs, social systems, local services and resources, and infrastructure for independence. There is limited investigation about collaboration among nurses, community providers, and healthcare leaders, especially from the perspective of the nurses. The objective of this report was to describe two nurses' perspectives about their collaboration with a research team in a community-based study. The research intervention included end-of-life conversations among members of underserved communities residing in a rural area in the western United States. The two nurses served as hosts/event planners for the intervention at a local community and senior center. Recruitment was conducted through social media, flyers, networking with local organizations, and word-of-mouth. Fourteen participants from underserved communities participated in the Hello game, which stimulated end-of-life conversations. The nurses reported collaboration challenges related to communication, consistency, and transparency. This report discusses these challenges from their perspective and offers salient points about their collaborative experience as a foundation for future successful collaboration with the potential to improve healthcare for underserved communities.

Key Words: Collaboration, nurses, nurses' perspective, transparency, communication, underserved communities, rural area, community-based research

Community-based research is an effective mechanism for interacting with local populations and understanding their needs, desires, and expectations for healthcare. Such research can lead to improved healthcare and its sustainability within the communities. Collaborating with governmental and non-governmental organizations in community-based research enhances the applicability of the outcomes to the health needs of communities (Melo & Alves, 2019; Watanabe et al., 2023; Williams et al., 2022; Williams et al., 2024). Over time, this collaboration emphasizes specific health issues and concerns for improving healthcare within these communities (Walker et al., 2000).

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It is imperative for nurses to be involved in research collaborations from the initiation to the conclusion to promote healthcare with lasting effects. Collaborations can facilitate nurses' ability to recognize the needs of underserved communities and consider strategies for holistic and community-oriented care to address the needs (Melo & Alves, 2019). Collaborating with any organization executing community-based research can potentially develop nurses' professional relationships with the communities and researchers (Williams et al., 2024). This effort will enhance their capacity to proactively care for people who live in these communities while advancing their roles as leaders and advocates for improved healthcare. However, there is limited information about collaboration between organizations and nurses in community-based research with underserved communities.

The Project Talk Trial is an example of community-based research in the context of end-of-life conversations (Van Scoy et al., 2022). This National Institutes of Health (NIH) sponsored trial is a five year initiative that includes collaboration between university researchers, the Hospice

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Foundation of America (HFA), and local hosts/event planners (Project Talk, 2025). This collaboration may provide several salient points to positively facilitate all stages of the community-based research (e.g., beginning, planning, implementing/executing, and evaluating) from the perspective of the two nurse participants. This report explores the collaborative experiences to identify salient points for future community-based research between nurses, organizations, and underserved communities.

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Background

End-of-life conversations facilitate meaningful sharing of information about personal values, goals, and priorities.

Navigating end-of-life care involves conversations about a person's directions and instructions for the process, and depends on that person's level of preparation for and understanding of end of life (Goswami, 2021). End-of-life conversations facilitate meaningful sharing of information about personal values, goals, and priorities. However, the completion rate for end-of-life conversations in the general population is low, ~60%, and among underserved communities, it is even lower, ~25% (Harrison et al., 2016; Malani et al., 2021; Nouri et al., 2020). Not engaging in these conversations often means that family members and/or caregivers have no direction about a person's preferences for end-of-life care, especially if the person cannot communicate them. Lack of meaningful sharing can precipitate care that is unwanted, burdensome, and potentially traumatic for family members.

Study Methods

The Hello game effectively promotes conversations around advance care planning.

The Project Talk Trial is a three-armed, randomized blinded intervention study that aimed to evaluate and compare the effectiveness of the Hello game and the Conversation Project for end-of-life conversations by persons living in underserved communities (Van Scoy et al., 2022). Briefly, the Hello game, formerly known as *My Gift of Grace*, is an end-of-life conversation game. It is played in small groups, generally between two and six persons, and uses a booklet of questions that spur thought and conversation about death and dying. One person reads the question aloud, all players write down their answers, and all players take turns sharing their answers. Players are also provided "thank you" chips which are bestowed to show appreciation of another player/player's response. Before starting the game, a coin flip (which is not revealed until the game is over) determines if the person with the most chips or with the least chips "wins." The game was developed through focus groups that involved over 100 patients and caregivers (Van Scoy, Scott, et al., 2017). It has been further refined following feedback from participants and researchers, and from the developers' direct experience observing individuals and groups while playing (Radhakrishnan et al., 2019; Van Scoy, Green, et al., 2017; Van Scoy, Reading, et al., 2017). The Hello game effectively promotes conversations around advance care planning.

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The Project Talk Trial relies on the use of hosts/event planners who received training and specific guidelines to recruit participants from the targeted underserved communities, host the event, and facilitate the intervention. The ideal host/event planner is engaged with the targeted underserved community members, invested in the goal to increase the completion rate of end-of-life conversations in the community, and invested in the larger research goal to improve the healthcare of the community (Steel, 2008; Van Scoy et al., 2022). We sought potential sites for the event that were accessible and relevant to the targeted community. Acceptable hosts/event planners can be community members, researchers from local universities, and/or practitioners within the community (Steel, 2008).

Beginning Stage

In our Project Talk Trial event, recruitment was initiated when the Registered Nurse Case Manager (RNCM) attended a webinar about advance care planning and end-of-life conversations among Native Americans/Alaska Natives. The RNCM was employed at a tribal healthcare clinic and has a background in research and end-of-life care. The RNCM first met virtually with the Project Talk Trial research team to explore the potential for the RNCM hosting an event for the community with which she worked. However, the targeted underserved communities did not include Native Americans/Alaska Natives. The research team inquired if the RNCM was willing to host an event aimed at the targeted underserved communities. The RNCM agreed to host/plan an event for the local, rural community, given her prior experience with the Hello game and an underserved population. The RNCM then secured assistance to plan and host the event from a university nurse researcher who did not have prior experience with the Hello game. The RNCM and university nurse researcher (i.e., the two nurses) were approved as hosts/event planners and randomized to one of the three conversational tools (the Hello game, the Conversation Starter Guide, or the TableTopics game). The two nurses were randomized to the Hello game tool for the local community event. This process established the pre-beginning of the experience, and provided a nursing perspective from clinical nursing practice and nursing research.

During the beginning stage, members of the research team met with the two nurses to discuss the expected responsibilities of hosts/event planners, the event, and the function of the research team members attending the event (Project Talk Trial, 2024). Responsibilities of the hosts/event planners related to recruiting, planning, and facilitating the execution of the event. The attending research team members obtained informed consent and administered pre- and post-tests to participants. The research team also handled all procedures, analyses, and deliberations (i.e., questions or concerns from participants) beyond this point. In sum, the beginning stage entailed solidifying expected responsibilities of the hosts/event planners, as determined by the research team.

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Planning Stage

For this stage, the Project Talk Trial initiative provided $300, the Hello game, and advance care planning materials developed by the research team (Van Scoy et al., 2022).This stage centered on participant attendance to the event for their engagement in cogent end-of-life conversations.

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The challenges or issues that we identified at this stage included 1) scheduling the event to align with the availability of most potential participants and the Project Talk Trial research team, 2) avoiding the pending winter conditions in the local area, and 3) selecting a well-known site for the event. The event was scheduled for October 26, 2023 since this date included a local holiday which corresponded to the research team's availability. Winter conditions in the area often occurred after October and included icy roads, unplowed areas of snow, and a temperature below 32°F-conditions that could likely affect attendance. The event occurred at a local community and senior center adjacent to the tribal healthcare clinic where the RNMC practices. This local community center is frequently used by the surrounding underserved communities with diverse patrons, safety measures, and a comfortable atmosphere. The center has ample restrooms, ample parking, and access to major roads/public transportation.

Recruitment happened during the four weeks prior to the event. Persons from both the targeted and non-targeted underserved communities were recruited. Refreshments reflected local preferences, a range of diets. We considered accessibility for minimal disruption of the event, from the reading of the instructions to the execution of the post-test (Segovis et al., 2007).

Implementation Stage

On October 26th, 2023, the tribal healthcare clinic joined a nationwide effort to promote end-of-life conversations. A research assistant from the research team attended. The event occurred from 5:15-8:15 pm in a meeting room at a local community and senior center in Douglas County in Nevada. Fourteen participants attended, who were from various ethnicities, economic statuses, and who were at least 21 years of age. There were 6 groups with at least 2 participants per group. Most participants had prior interaction(s) with others in the group. The agenda consisted of five parts, described below in the Table.

Table. ***End of Life Conversations Agenda***

Part 1: 5:15 – 5:40	Welcome, introductions, and research questions.
Part 2: 5:40 – 6:10	Instructions: Hello game; participants were encouraged to take breaks as needed, which included getting refreshments and/or using the restrooms.
Part 3: 6:10 – 7:10	Play the Hello game.
Part 4: 7:10 – 7:50	Food and refreshment provided; wrap up Hello game.
Part 5: 7:50 – 8:25	Research questions, distribution of follow-up materials, distribution of thank you/gift card, and dismissal.

Three moderators engaged in the execution of the event, the two nurses and a Project Talk Trial research assistant. The research assistant strictly adhered to the protocol while the two nurses considered participants' needs without major deviation(s) from the protocol. Preliminary end-of-life conversations actually commenced in Part 1 instead of Part 3. Participants often sought out clarification from the RNMC (instead of the research assistant) about the instructions and/or research questions. Addressing these challenges or issues involved collaboration among the moderators. For example, the approach of the RNs reflected the decision to follow the lead of the research assistant while making subtle/minor adjustments to encourage participants to continue playing the Hello game. The two nurses assisted the research assistant in Part 5 in a manner that presented no deviation(s) in the process. This consistency was important when asking research questions and recording the participant answers. Consequently, addressing the challenges or issues in this stage centered around consistency and transparency in the execution of the event.

Evaluation Stage

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The event was a success with the Hello game stimulating end-of-life conversations, which started during Part 1 of the event. These conversations continued throughout the event; they were passionate, open, direct, reflective, and thought-provoking. Participants interacted with the two nurses and welcomed feedback about the process. They shared their appreciation for the ability to participate in the local event for the Project Talk Trial, expressed a desire to continue the end-of-life conversations with their loved ones, and agreed to consider completing an advance directive. Participants left the event with "doggie bags" and a gift card as mementos of the event. These outcomes were positive indicators that the environment felt safe, friendly, non-threatening, and comfortable. Site administrators expressed an appreciation for conducting the research at this setting. They enjoyed working with the two nurses and looked forward to future collaborations.

Overall, our challenges related to communication, consistency, and transparency with the Project Talk Trial research team. The two nurses' responsibilities were designed to be consistent with those of the other hosts/event planners in the nationwide trial. This national level plan closely regulated the effect(s) of the hosts/event planners on the trial. It also minimized the use of the two nurses' background in the event. Utilizing more of the two nurses' background, such as the previous experience in underserved communities by the nurse employed at the tribal healthcare clinic and the research expertise of the university affiliated nurse, might have communicated individual concerns of the communities. This additional knowledge or insight might have enhanced the recruitment and the planning and implementing of the Hello game.

The event, although successful overall, had issues related to communication and transparency…

Transition from one stage to the next required extra communication and consistency in the execution to understand the participants' perception of the Hello game. Their reaction and response indicated a disconnect between the game and their individual cultures. For example, limited transparency demonstrated a need for adjustment of the Hello game. Further transparency was needed about the future plans for the use of data from non-targeted underserved communities in the Project Talk Trial. While Native Americans/Alaska Natives were welcomed to attend the local event, there was no discussion about how their attendance would inform the local event for the Project Talk Trial. This discussion for transparency did not occur until several months after the local event. The research team shared the plan to execute a trial tailored to the Native Americans/Alaska Natives community with the goal of modifying the Hello game to be culturally appropriate for Native Americans/Alaska Natives. This moment of transparency was appreciated. However, this transparency did not address other questions posed by the two nurses, which impacted the relationship and trust between the two nurses and the research team. The event, although successful overall, had issues related to communication and transparency which were shared by other hosts/event planners (Project Talk Trial, 2024).

Discussion

This is one of the first formal reports about collaboration from the perspective of nurses who served as the local hosts/event planners for this community-based study initiative. The local hosts/event planners' (i.e., the two nurses) experience with the Project Talk Trial reflects similar experiences and complications shared by previous hosts/event planners (Project Talk Trial, 2024). The Project Talk Trial research team has responded to some of the questions and concerns raised by the two nurses.

Collaboration can be a rich and rewarding experience that can foster future collaborations.

As previously noted, challenges from the collaboration related to communication, consistency, and transparency that could potentially impact future projects. The Project Talk Trial created the role used for the two nurses in this study with basic responsibilities equal to those for all hosts/event planners in this nation-wide study (Project Talk Trial, 2024; Van Scoy et al., 2022). However, their responsibilities did not take advantage of their background related to end-of-life conversations, advance care planning, or research; these areas of expertise may have strengthened the planning and implementation of the local event. The event was judged successful although the collaboration was a challenging experience. From the perspective of the two nurses, the following salient points emerged that might better contribute to a productive collaboration:

- Assess any collaboration for constructive outcomes.
- Expect responses to any or all questions and be willing to provide responses to questions.
- Be clear and transparent about your expectations, ensuring their alignment with the expectations of all collaborators.

- Be prepared to ask questions with a high potential for answers. For example, in this local event, questions related to the selection of the targeted population have a high potential to be answered. Questions related to the rationale of not recruiting certain ethnic groups have a low potential to be answered because it may cause the research team to recognize a bias or the need to re-design the study.
- Be prepared to listen and learn instead of hearing and reacting.
- Discuss thoroughly how expectations can be achieved.
- Understand that collaboration is a joint endeavor with the merging of backgrounds and skill sets through mutual respect, trust, and effective communication.
- Recognize that collaboration can be used to present a unified present for solidarity in purpose, goals, and outcomes.
- Be willing to walk away and pursue other collaborative options within the community. For example, in our study, failure to modify the agenda for participants' individual needs would justify leaving the study as host/event planner because it would conflict with the purpose of the study - stimulating end-of-life conversations.

These salient points endorse the importance of trust, transparency, respect, consistency, communication, and networking within the community. Collaboration can be a rich and rewarding experience that can foster future collaborations. In addition, these salient points align with the Sigma Theta Tau International guidelines for national and international collaborations (Walker et al., 2000).

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The points also relate to other outcomes that emerged from the experience. The nurses networked with a NIH-sponsored research team. The collaboration emphasized efforts to improve the healthcare of the underserved community, further enhancing the potential for community partnerships (Walker et al., 2000). The nurses learned the importance of being direct and informed about expected roles when participating in any collaborative activities. They expanded their capacity to engage the underserved communities in community-based research and to advocate for the communities' right. Furthermore, the two nurses learned about NIH-sponsored resources to improve healthcare for the underserved communities. These salient points are foundational in any successful collaboration with unbiased directions and potential for professional growth (Walker et al., 2000).

Findings from this report are supported by studies that have examined collaboration between nurses and organizations in community-based research. Our proffered salient points emphasize the empowerment of the nurses with the capacity to also empower members of the underserved community (Melo & Alves, 2019). Promoting community members to participate actively in community-based research may empower the wider community by developing a unified social system, growing leaders and protectors of the community, and establishing the potential for internal and external partnerships (Melo & Alves, 2019). This empowerment promotes nurses' capacity to work with community leaders and/or gatekeepers to access community resources while supporting the community infrastructure (Melo & Alves, 2019). Collaboration is the manifestation of empowerment through community partnerships that are instrumental in solving community health issues, delivery of healthcare, and independence in care (Melo & Alves, 2019). As a result, the community enhances its ability to claim ownership of the neighborhoods, partner with nurses, and sustain community growth.

Promoting active participation by members in community-based research may empower the wider community by developing a unified social system, growing leaders and protectors of the community...

Certain salient points relate to the capacity of nurses as change agents, advocates, and builders of solidary within underserved communities. This capacity is defined by transparency, mutual respect and trust, and open communication in the collaboration. The perceptions of the nurses who participated in this research study event were supported by the results of a focus group about collaboration between public health nurses and general practitioners, which impacted the community (Watanabe et al., 2023). The emerging themes related to a strengthening of the roles of healthcare providers in the community where they promoted change in the community's awareness and behaviors. These changes often were new perspectives about the health issues of the community through sympathy and consultation, which align with the possible outcomes from our salient points. Other themes were a sense of trust, solidarity, proactive changes, and respect of the culture for the community (Watanabe et al., 2023). Furthermore, positive collaboration was identified in a grounded theory study characterizing the collaboration between Nurse-Family Partnership (NFP) nursing home visitors, healthcare providers, and community support services (Williams et al., 2022). Key similar themes in that study were leadership commitment, supporters of providers, shared perceptions, trust, respect and value, and partnership referrals and outreach efforts. Through these themes, all collaborators were able to channel their efforts unbiasedly to improve the healthcare of the underserved community.

Our salient points indicate ways of dealing with changes, positive or negative, in the collaboration. The relationship between nurses and underserved communities can precipitate these changes. This interpretation of the salient points is substantiated by the results of a web-based survey completed by NFP supervisors and community providers at three annual time points over a 4-year period (Williams et al., 2024). Collaboration between NFP nursing supervisors and community providers impacted the integration, coordination, and implementation of care delivered to underserved communities (Williams et al., 2024). These changes may have stemmed from possible dissonance about the collaborators' understanding of their responsibilities, roles, and expectations, especially in defining the care delivered to members of underserved communities. As our salient points highlight, collaboration can only succeed if there is transparency and communication about the goals, knowledge, and mutual respect between collaborators. It is important to recognize and respect the strengths and limitations of each collaborator, building on the collaborators' strengths and potential (Williams et al., 2024).

Implications for Nursing

Nurses can leverage collaboration in community-based research to improve the healthcare of people who live in underserved communities. Through collaboration, nurses minimize the occurrence of helicopter research, whereby outsiders only come into a community to gather data and leave without establishing a relationship to offer support for better healthcare within the community. Nurses promote these relationships for an understanding about local resources, outreach approaches, community issues, health needs, and misperceptions and misunderstandings for improved healthcare and delivery. Collaboration makes a tremendous difference in the healthcare provided in underserved communities and promotes trust in the healthcare system. Collaboration in community-based research provides nurses with an innovative entry to engage in a research experience with organizations and local communities, while learning how to develop this trusted relationship.

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This report has highlighted the potential of nurses to engage in collaboration with the capacity to protect the community's rights and advocate for community participatory research. The emerged salient points demonstrate the importance of nurse involvement related to the ability to advocate for participants' autonomy, rights, and justice, thus strengthening the robustness of the research. Nurses are trained to meet and deal with challenging situations so that when they occur in collaboration, they can navigate the situation(s) for positive and productive outcomes within the research. This was the case with the two nurses described in this report. Nurses possess an important ability to work within challenging conditions so that the outcome positively contributes to the targeted goal. Nurses are change agents, who can significantly improve the collaboration for all persons. Therefore, it is hoped that nurses in future collaborations can consider these salient points to support a rewarding experience.

Limitations

This local community event was limited by marketing. Increased marketing might have increased the recruitment of participants from more rural areas. This limitation minimizes the generalizability of the data so that it is specific only to the attending participants. Another limitation was minimal use of the local hosts/event planners' background in designing the marketing and recruitment materials for the targeted communities. Attending participants were from rural areas, but not necessarily from the originally targeted underserved community. These limitations can be addressed in future collaborations by including the local hosts/event planners in the design of marketing and recruitment materials.

Conclusion

Nurses provide a safe and comfortable environment for sensible, informal interactions without judgmental or biased responses.

Collaboration by nurses in community-based research demonstrates an outreach effort to improve healthcare for members of underserved communities. Nurses provide a safe and comfortable environment for sensible, informal interactions without judgmental or biased responses. They are able to recognize needs, concerns, awareness, and sensitivities of the people who live in these communities. Importantly, there is the increased networking inherent to collaborative community centered research that can bring healthcare resources and services to the community while promoting independence, self-assurance, and health promotion. There will be challenges in collaborations, but they can be minimized by communicating shared expectations; creating transparent goals, objectives, and actions/behaviors; demonstrating mutual respect; and maintaining objectivity throughout the process. In the end, collaboration can be a positive and rewarding experience for nurses to establish supportive partnerships with communities and organizations for one shared goal— to improve the healthcare of those who live in underserved communities.

Declaration of Conflict of Interest

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[Medical Aid in Dying in the United States: Review, Discussion and Guidance for Nurses]

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