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Practical Strategies to Circumvent and/or Surmount Six Barriers in Health Disparities Research: Observations from a Pilot Project Among Vietnamese Americans

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Abstract

This paper describes six practical strategies to circumvent and/or surmount barriers encountered in community-based health disparities research, as illustrated within a pilot study on Vietnamese Americans' perceptions of the US healthcare system. Health issues, including higher rates of cancer in this group, prompted the current study. These six strategies include the following: (1) identify a population with health concerns, (2) establish the role of the community partner early, (3) recruit an investigator who understands not only the language and culture but also the research process, (4) accept the exploratory nature of a study in an understudied group, (5) put in place the groundwork for recontacting community members, and (6) assemble a motivated research team. The descriptive experience reported here might enable other investigators to undertake and complete work in the field of health disparities in minority groups.

Keywords

Vietnamese; Americans; Health disparities; Survey

Introduction

Health disparities persist in the USA: race still determines who receives potentially curative surgery for early-stage non-small cell lung cancer, Native Americans die from tuberculosis at a 560% higher rate, and analgesics are prescribed to white patients at nearly twice the rate compared to African Americans in some regions [1–3]. The impetus to study health disparities remains strong despite an abundant literature that describes the challenges of conducting such research. The importance of forging trust between members of the community and the investigative team is well discussed [4–8]. However, to our knowledge, few reports describe the hands-on, practical issues encountered when launching a seemingly straightforward pilot project within a specific ethnic minority group.

To fill this gap, we describe an ongoing pilot project that serves to illustrate six practical strategies to either circumvent and/or surmount barriers that might arise in health disparities research within a minority population. This pilot project consisted of a cross-sectional survey of older Vietnamese Americans to capture this group's perceptions of the American healthcare system. Because health problems—particularly cancer—from war exposure and aging are prevalent among Vietnamese military officers and because such health problems

spawn interactions with the American healthcare system, we decided to focus upon former Republic of Vietnam military officers who had come to the USA as refugees. This manuscript describes six strategies to either circumvent and/or surmount barriers that arose during the conduct of this pilot study.

- 1 Identify a group with health disparities. Vietnamese Americans are a growing population, and they have healthcare needs. With over 1.2 million Vietnamese living in the USA [9], the Vietnamese constitute the fifth largest Asian/Pacific Islander group in the USA. There has been an 85% increase in the number of Vietnamese living in the USA compared to a decade ago [10]. The majority of Vietnamese immigrated to the USA after the fall of the Republic of Vietnam in 1975; and since then, this population has continued to grow [11]. This group will be the second largest Asian Pacific/Islander ethnic group, next to Chinese Americans, by 2030 [9].

Importantly, healthcare disparities currently exist among Vietnamese Americans. Over 40% of Vietnamese men in the USA smoke [12], and, as a result, this group has an 18% higher rate of lung cancer compared to white men [13]. For reasons that remain only partially explained, Vietnamese also have relatively high rates of hepatocellular carcinoma, gastric cancer, invasive cervical cancer, and non-Hodgkin's lymphoma [13]. These statistics provide a strong rationale and motivation to focus on this ethnic group.

- 2 Establish the role of the community partner up front. Previous studies demonstrate how a community partnership provides insight into community norms and builds trust within the community [14–18]. Sensitive to such precedent, our study team sought the advice of a community partner, a former Vietnamese military officer, and engaged his help early on. After learning the study team's motivations and the goals of the project, this individual was willing to introduce our project to his military colleagues, inform them of upcoming correspondence from the investigative team, and allow his name and signature to be attached to future correspondence, as appropriate.

Although engaging a community partner is not unique, to our knowledge, the need to define the role of this partner has not been as extensively discussed in the literature, particularly when that partner is involved with only a single pilot project and not serving as part of an advisory board or coalition. The study team soon found itself having to ask and answer the question, “Is this community partner really a member of the study team or not?”

This question is important for three reasons. First, from a theoretical standpoint, if this community partner were truly a member of the investigative team, his loyalties to the community could be called into question. To maintain the stature of this community partner as unambiguously and exclusively aligned with the community, we decided that this partner best serve solely in the role of community partner, not as a member of the study team. Second, when submitting our project proposal to the Institutional Review Board (IRB), this question emerged again. The fact that our community partner was not an employee of an academic institution, had not received previous training in research, and therefore could not take an examination in human subjects' research training further clarified his role as a community partner, not a member of the study team. In turn, we assured our IRB that our community partner would have no access to study data over and above that offered to any other study participant. Third, defining this community partner as only a community partner allowed this individual to complete all aspects of the study, as a study participant. Our community partner viewed this latter opportunity favorably and felt that in this exclusive role he could advocate for his military officer colleagues with no conflict of interest.

Admittedly, certain projects might require that the community partner be a bona fide member of the study team, but the main point here is that this question of role delineation and ultimate loyalty may arise and, if it does, it will require an answer. The investigative team should anticipate this question and seek to answer it early on in order to move the project forward expeditiously.

- 3 Recruit an investigator who understands not only the language and the culture but also the research process. In contrast to point no. 2 above, having a Vietnamese researcher/physician serve as an integral member of the team turned out to be invaluable. PLN served in this role and was instrumental in candidly discussing problems, often before they arose. One such example is described below.

Despite the fact that our study team member, PLN, was fluent in Vietnamese, our institution's IRB required that its own extramural vendor translate documents and provide a certificate of authenticity to this effect. Upon receiving the translated documents, PLN observed that some aspects of this translation would not be acceptable to military officers from the former Republic of South Vietnam. The translated document referred to the "former Republic of South Vietnam" as "the old regime," a term which would not have been well received by a group who had spent the greater part of their livelihood in defending this government. Other less egregious but nonetheless gauche issues arose throughout the translated document: the word "officer" was translated into "quân nhân," which meant "soldier;" "former military officer" was translated to "quân nhân cũ," which meant "old soldier," whereas the correct translation should have been "cũ sĩ quan." These aberrancies could not be attributed exclusively to the possibility of an outsourced translation from communist Vietnam because some aspects of the translation were also grammatically awkward: "to contact" was translated as "liên h," which meant "to connect" or "to relate," whereas the correct translation should have been "liên lạc." In short, such variations in vocabulary resulted in a document that many former military officers may have been uncomfortable reading.

Had our study team lacked an investigator fluent in the language and sensitive to the culture, such wording might have lowered our survey response rates and closed doors to future investigation within this community. Moreover, such mistakes might even have led our own community partner to shy away from maintaining his partnership with us.

How were these issues resolved? Members of our investigative team undertook multiple conversations with our institution's IRB leadership, other Vietnamese translators, other members of the language department at our institution, and other staff members fluent in Vietnamese. We retranslated some portions of the document ourselves; and, given the challenges of using the available English-specific software and keyboards, we utilized an online Vietnamese dictionary to insert the necessary accent marks. Ultimately, the IRB permitted another Vietnamese-fluent staff member who was not a member of our investigative team to serve as an ad hoc IRB member and to review and approve a modified set of documents.

This translation process took over 3 months. Although the initiation of our project would no doubt have moved far more expeditiously had we remained oblivious to these translation issues, we believe survey response rates and future contacts with this community would have inevitably suffered.

- 4 Accept the exploratory nature of a study in an understudied, minority population. To our knowledge, this survey-based study was the first of its kind within this population. This aspect of the study—coupled with what we perceived as an urgent need to help aging and ailing members of this group—

prompted us to accept less rigorous aspects of the study design. First, we decided to accept all mailed survey responses in an anonymous fashion and not to use unique identifiers to track responses. Talking informally with epidemiologists and survey researchers at our institution, we learned of preliminary, unpublished data that suggest survey response rates drop if unique identifiers and Health Insurance Portability and Accountability Act forms are used. Although the absence of these might predispose to undetected duplicate responses after a second mailing, we nonetheless decided not to use either. These approaches seemed appropriate in an exploratory survey from which a large volume of preliminary qualitative data is sought.

Second, we acknowledged that some of these military officers were likely deceased. The question arose whether it would be worthwhile to gather information about the deceased military officer from a family member. Although this approach could cause confusion in interpreting results—particularly because family members may describe their own personal experiences and omit information about the deceased—we decided that in an exploratory study, such as this one, any information from this community would be valuable. We also noted that learning about family members' perspectives would potentially provide more complete information on military officers' end-of-life issues [19].

Third, to our knowledge, no Vietnamese language surveys that assess perceptions of the American healthcare system are available. After much research, the study team decided to utilize the Patient Satisfaction Questionnaire Short Form (PSQ-18) because this instrument met our goals and had been validated, albeit in English [20]. The brevity of the PSQ-18 might also lead to higher response rates [21]. We translated this questionnaire, formulated other questions, invited write-in comments, and included an open-ended response format. Thus, although we lacked a previously validated questionnaire, the utilization of a brief questionnaire that had been validated in another language and the incorporation of a mixed-methods approach seemed acceptable for an initial foray into understanding this understudied population.

Fourth, our study team decided to survey only a small subpopulation of former military officers, examine results, and then decide on whether survey methods should be modified or maintained. By surveying fewer than 100 people, unanticipated problems could be easily identified and corrected so that valid results could be subsequently garnered from a larger population.

- 5 Lay the groundwork for recontact. Our team worked hard to try to ensure that future studies remain feasible. Katz noted that community-based participatory research requires developing relationships, sharing observations with community members, embracing diverse perspectives, using community-appropriate and -appreciated research methodology, and valuing the knowledge from the community, as gained outside the walls of academia [22]. Such principles were adhered to during this project: not only are they simply the right way to proceed, but they also helped ensure the possibility of future contact.

Along these lines, our investigative team recognized the value of sharing study results with all community members regardless of whether a specific community member had completed the survey. This sharing would provide closure for the community on this specific project. Although we have not initiated this process yet, we intend to do so after study results are analyzed and interpreted. Again, this sharing keeps doors open for future investigation and will allow for back-and-forth communication between the study team and the community.

While compensation and incentives are commonplace in research, we attempted to be culturally sensitive on this point. We included a packet of tea with both the first and second

requests for survey completion. The widespread consumption of tea in many Asian cultures coupled with the pleasing aroma of the tea that accompanied each mailing seemed to make this beverage an appropriate “thank you” gift.

- 6 Assemble a motivated research team. Finally, we think it is important that an investigative team be strongly motivated—indeed, unwavering—in its desire to move forward with a project such as the one described above. We had strong personal motivations. This team consisted of EKS, who had worked in implementing health disparities initiatives for several years among Vietnamese Americans. This previous hands-on contact provided incentive to further such efforts. It also consisted of PLN, a researcher/physician of Vietnamese descent. This investigator had personal reasons for focusing on healthcare disparities among Vietnamese Americans. The team also included AJ, a medical oncologist who, because of the notably high cancer rates among Vietnamese Americans and because of an interest in geriatric oncology, very much wanted to undertake and complete the project described here. In the absence of such a motivated investigative team, we believe our project might have languished.

Conclusion

Currently, we continue to collect completed surveys. The preliminary response rate sits at 25% after the first mailing, and we anticipate the final response rate will be higher. This preliminary response rate is similar to other studies perhaps conducted under less challenging circumstances and suggests that the methodology described above was effective [23, 24].

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