

Health Promotion via Deaf-Friendly Ministries

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Abstract Deaf community members face many barriers to accessing health information. This paper discusses the feasibility of creating a nationwide network of Deaf-friendly ministries to help disseminate cancer information in American Sign Language (ASL) to the Deaf community. Deaf-friendly ministries ($N=403$), identified through Internet searches and one-on-one referrals, were sent up to three mailed invitations to join the network. Over half of the ministries responded, with 191 (47.4 %) of the ministries joining the network, completing a baseline survey and receiving ASL cancer education videos to share with members of their congregation and community. Fifteen (3.7 %) responded that they were not interested or no longer had a Deaf-friendly ministry; the rest did not respond or their invitations were returned as undeliverable. As the program progressed, an additional 238 Deaf-friendly ministries were identified. To date, 61 (25.6 %) agreed to participate after the single invitation that was mailed. This network

of Deaf-friendly ministries offers a promising dissemination partner.

Keywords Cancer · Education · Deaf · Disparities · Dissemination · Early Detection · Health Promotion

Introduction

Members of the Deaf Community share much in common with other linguistic and cultural minority groups, including limited English language literacy and barriers to accessing health information [1]. In addition, the Deaf community faces unique barriers, such as not sharing a common language with their own family members. There are very few health care providers who are proficient in American Sign Language (ASL), the language of the Deaf community, competent in Deaf culture [11], or who are Deaf themselves.

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Furthermore, many clinicians tend to view deafness from a pathological perspective that offends the Deaf community [1, 12]. These factors have led the Deaf community to access medical information in different ways than the hearing population. For example, the Deaf community is less likely than hearing individuals to receive preventative medical information from physicians, television, books and the radio, and more likely to receive preventative medical information from a Deaf club [15]. However, due to the Deaf community's higher rate of inaccurate information obtained from healthcare providers [10, 13, 15, 21] and lower rate of health literacy [16], the value of shared information among members of the Deaf community is circumspect. Furthermore, a study by Barnett and Franks [2] showed that the Deaf community places a lower reliance on health care providers as a source for information and care. Alternate strategies for improving the Deaf community's access to health information are necessary.

To provide the Deaf community with better access to cancer control information, the Moores UCSD Cancer Center created a series of culturally competent cancer education videos in ASL and open captioning. The videos included many illustrations and summary slides to facilitate the transmission of complex cancer information. Voice overlay was added, and background music was omitted so the information could be equally well accessed by hard-of-hearing and hearing people [5]. The videos were evaluated scientifically to assure that no misinformation was being conveyed and to determine whether the videos produced increases in viewers' short- and long-term cancer knowledge [3, 8, 9, 19, 23]. The videos were also submitted to international, professionally juried video competitions to evaluate their creative merit and professional qualities. The series has received two dozen awards to date. Following these positive evaluations, the next step was to find methods of disseminating the videos to a national audience.

While the lack of health information in ASL is a clear challenge to addressing the Deaf community's health disparities, an equally pressing issue is the lack of proven dissemination strategies for efficiently delivering education programs to the Deaf community. Ministries have played an important role in promoting the health of their congregations [18], particularly among African American and Hispanic American communities [4, 6, 7, 17, 20, 22]. The authors recognized that some ministries were known to be Deaf-friendly, offering services or interpretation in ASL. This paper reports on a demonstration project to evaluate the feasibility of using Deaf-friendly ministries as a strategy for disseminating these cancer education videos to people who rely upon ASL as their preferred means of communication. This demonstration project tested two related hypotheses:

- (1) At least 50 Deaf-friendly ministries can be identified across the United States that might be recruited to create a nationwide, community-based cancer education dissemination network.
- (2) At least 25 % of the identified Deaf-friendly ministries will actually consent to help researchers evaluate the ministries' effectiveness as dissemination partners for the project's cancer education videos.

Methods

For this study, “Deaf-friendly ministries” were defined as places of worship: churches, synagogues, temples, and others that regularly have services in ASL and/or provide ASL interpreters. The primary strategy for identifying Deaf-friendly ministries was through Internet searches for Deaf-friendly ministries. A second strategy was to collect referrals to Deaf-friendly ministries from people who attended national meetings for the Deaf. Additional referrals were received from members of ministries who were already participating in the partnership.

Each ministry's spiritual leader was sent a short executive summary and an in-depth letter explaining the study and inviting the ministry to join the free cancer education partnership. They were told that participating ministries would receive a series of free cancer education videos for their Deaf congregation and community members and their hard-of-hearing and hearing loved ones. The letter explained that the project was funded by the National Cancer Institute, and that the educational partners conducting the project were the Moores USCD Cancer Center, Deaf Community Services of San Diego, Inc., Gallaudet University, the National Association of the Deaf, and Bovee Productions.

To enroll in the education partnership, ministries needed to complete a brief IRB-approved questionnaire (IRB-approved implied consent) regarding the characteristics of their organization's Deaf ministry, such as the number of Deaf and hard-of-hearing members who regularly attended services. Up to two additional invitations were sent to non-responding ministries. The ministries that responded to one of these invitations were immediately sent a copy of the partnership's first cancer education video about breast cancer and a brief follow-up survey inquiring about the viewers' impressions of the video. Subsequent videos and surveys were sent once previous surveys were returned. Follow-up surveys were sent up to two times to non-responding ministries.

Deaf community advisors assisted in the development of all invitation materials to assure that they were culturally appropriate and that the English phrasing of the questions was linguistically accessible even to a respondent with limited English language proficiency. Due to the Deaf

community's limited prior exposure to research studies, the Deaf community advisors also sought to ensure that the questionnaire was neither intimidating nor burdensome. This was particularly important for this study as budgetary constraints prevented the use of incentives to encourage participation and responsiveness.

Results

Hypothesis #1 was proven true. The research team engaged in an exhaustive exploration of the Internet and sent queries to members of the Deaf community around the country to identify Deaf-friendly ministries. This strategy produced an initial list of 403 Deaf-friendly ministries across the USA and Puerto Rico. This was far in excess of the minimum of at least 50 Deaf-friendly ministries that were hypothesized to be identifiable. Just as the Deaf population clusters in select geographic areas, so did the Deaf-friendly ministries that serve the community, with the number identified varying by state from 0 to 72. The 403 ministries came from 42 states. Not represented among initial list of 403 Deaf-friendly ministries were: Maine, Mississippi, New Hampshire, North Dakota, Rhode Island, Vermont, West Virginia, and Wyoming.

In the course of reporting the study's progress at scientific meetings and national Deaf community conferences, as well as continued Internet explorations, an additional 238 Deaf-friendly ministries were identified. This resulted in the identification of ministries in every state and the cumulative distribution of ministries increased to between 1 and 105 by state.

The second hypothesis was also proven true, that at least 25 % of the identified Deaf-friendly ministries would actually consent to help researchers evaluate the ministries' effectiveness as dissemination partners for the project's cancer education videos. The 403 ministries identified were all given the same treatment described in the “Methods” section. Ministries that did not respond to the first invitation were sent two additional letters. Of these ministries, 191 (47.4 %) accepted one of the three invitations to join the partnership and were sent the first video. Of the remainder, 15 (3.7 %) ministries responded that they were not interested in participating or no longer had a Deaf-friendly ministry; the rest did not respond or their invitations were returned as undeliverable. While the proportion of positive responses diminished with each subsequent invitation to join the partnership, the continued accrual of new partners with each mailing underscored the value of sending multiple invitations to potential partners (see Table 1). The total number of ministries recruited as a result of the subsequent mailings was nearly 70 % greater than the number achieved with the first mailing alone. When the 191 Deaf-friendly ministries

Table 1 Effect of multiple invitations on recruiting deaf-friendly ministries ($N=403$)

| Recruitment letter | Identified ministries remaining | Recruited ministries | Cumulative recruitment |
|--------------------|---------------------------------|----------------------|------------------------|
| 1 | 403 | 113 (28.0 %) | 113 (28.0 %) |
| 2 | 290 | 69 (23.8 %) | 182 (45.2 %) |
| 3 | 221 | 9 (4.1 %) | 191 (47.2 %) |

that consented to participate were grouped by geographic region, participation ranged from 40.1 % for the Western states, to 69 % for the ministries in the Southern states (Table 2). The 191 participating ministries were located in 37 of the 50 states.

The additional 238 ministries that were identified as the program progressed received only a single letter of invitation, but where appropriate, the letters included a note that identified the person who was connecting the ministry with the program, making it a “warm” invitation (in marketing terms) rather than a “cold call.” Of the 238 ministries, 61 (25.6 %) accepted the invitation to participate. It was not possible to test the impact of subsequent mailings on the uptake due to budgetary constraints. When these 61 ministries were combined with the original group of 191 participating ministries, 42 states were represented in the network of participating Deaf-friendly ministries, leaving without representation in the network of Deaf-friendly ministries, the states of Maine, Mississippi, New Hampshire, North Dakota, Rhode Island, Vermont, West Virginia, and Wyoming, as well as the territory of Puerto Rico.

Discussion

The members of the Deaf community are different from other minority groups, largely due to the fact that as many as 96 % are not born into the Deaf community [14]. As a result, they are geographically widely distributed, making it difficult to create cost-efficient, culturally, and linguistically aligned health promotion programs for them. However, unlike other minority communities, they have readily embraced Internet technology to gain enhanced communication access to other community members, both near and far. This characteristic makes it possible to create educational programs that can be uploaded to the Internet, with the reasonable expectations that this tightly knit community will share beneficial knowledge.

The question then becomes how to trigger most quickly the viral delivery of a health education program. An ideal solution would be to have multiple, simultaneous information release points to achieve widespread delivery of a message and repeat cues to the message's call to action.

Table 2 Participation rates by region for ministries that completed the invitation process (*N*=403)

| Region | State | Number of ministries contacted | Number of participating ministries (response rate) |
|-----------|-------|--------------------------------|--|
| Northeast | CT | 3 | 3 |
| | MA | 4 | 2 |
| | ME | 0 | 0 |
| | NH | 0 | 0 |
| | NJ | 6 | 1 |
| | NY | 15 | 6 |
| | PA | 11 | 5 |
| | RI | 1 | 0 |
| | VT | 1 | 0 |
| | Total | 41 | 17 (41.5 %) |
| Midwest | IA | 10 | 6 |
| | IL | 49 | 16 |
| | IN | 7 | 7 |
| | KS | 5 | 5 |
| | MI | 8 | 5 |
| | MN | 6 | 3 |
| | MO | 9 | 5 |
| | ND | 0 | 0 |
| | NE | 3 | 1 |
| | OH | 15 | 8 |
| | SD | 1 | 1 |
| WI | 7 | 2 | |
| Total | 120 | 59 (49.2 %) | |
| South | AL | 7 | 3 |
| | AR | 2 | 1 |
| | DE | 0 | 0 |
| | FL | 14 | 3 |
| | GA | 8 | 5 |
| | KY | 9 | 8 |
| | LA | 7 | 5 |
| | MD | 14 | 8 |
| | MS | 3 | 0 |
| | NC | 10 | 6 |
| | OK | 8 | 4 |
| | SC | 6 | 3 |
| | TN | 7 | 4 |
| | TX | 23 | 13 |
| | VA | 11 | 6 |
| | WV | 0 | 0 |
| Total | 129 | 69 (53.5 %) | |
| West | AK | 0 | 1 |
| | AZ | 8 | 6 |
| | CA | 72 | 28 |
| | CO | 3 | 3 |
| | HI | 3 | 0 |
| | ID | 2 | 0 |

Table 2 (continued)

| Region | State | Number of ministries contacted | Number of participating ministries (response rate) |
|-------------|-------|--------------------------------|--|
| | MT | 1 | 1 |
| | NM | 1 | 1 |
| | NV | 1 | 0 |
| | OR | 3 | 1 |
| | UT | 5 | 0 |
| | WA | 13 | 5 |
| | WY | 0 | 0 |
| | Total | 112 | 46 (40.1 %) |
| Puerto Rico | | 1 | 0 (0 %) |
| Total | | 403 | 191 (47.4 %) |

Ministries have been effectively used as a dissemination strategy for many public health efforts designed for minority community delivery. While Deaf-friendly ministries were an important element of the Deaf community's infrastructure, a review of the scientific literature found no other studies that had explored the feasibility of a collaboration between health educators and Deaf-friendly ministries.

In this study, Deaf-friendly ministries were identified in all 50 states, and multiple ministries were found in those states with larger Deaf populations. Further, the response rate to up to three mailed invitations to join a previously unknown partnership was nearly 50 %. These findings suggest that Deaf-friendly ministries have the potential to become a nationwide dissemination network for public health educators and others concerned with achieving widespread social justice within this community.

Accrual to this research study was anticipated to be a problem because there was no prior relationship with the invited ministries, no opportunity for face-to-face interaction during the recruitment phase, and no incentive for participation. In spite of this, nearly half of the Deaf-friendly ministries formally agreed to participate.

Acquiring such a high response rate suggests that the methods used to identify and recruit the ministries were effective. The reminder letters sent to the first group of ministries proved to be a cost effective way of increasing the number of ministries. Sending multiple mailings to these ministries resulted in nearly a 70 % increase in participation. Judging from the success of multiple mailings with the first group of ministries, it is likely that additional mailings would have increased the participation rates for the second group.

Strategies employed during the second round of recruitment helped further the breath of the program. Continued Internet searches resulted in a more exhaustive list of ministries and one that was more geographically diverse. Giving presentations at regional and national meetings for the Deaf

community allowed the partnership to secure the community's input and assistance identifying and recruiting more Deaf-friendly ministries.

Nearly 70 % of the participating Deaf-friendly ministries fell into one of two categories. Of the 252 ministries, 48 % (121) were small ministries (congregations of ≤ 100) of predominantly Deaf members and 20.2 % (51) were large ministries (congregations of > 100) of predominantly hearing members with a smaller ministry for Deaf constituents nested within the larger hearing congregation (13 % (33) of ministries fell outside of these two groups, and 18.7 % (47) did not provide adequate congregational information to be categorized). Thus, for all but the small number of Deaf-friendly ministries with large congregations of Deaf individuals, the Deaf-friendly ministries tended to involve small numbers of Deaf members, reflective of the Deaf community's small overall size.

The small size of Deaf-friendly ministries makes them more likely to be run by volunteers rather than by paid staff. This could limit the feasibility of some Deaf-friendly ministries' participation in a cancer education partnership and might also increase the frequency of disruptive leadership changes. Alternatively, Deaf-friendly ministries may recognize that partnerships with health promotion educators can be an effective strategy for showcasing their Deaf-friendly ministries and hence, an effective means for attracting more members of the Deaf community to their ministry. Hence, such a partnership could be synergistic in achieving both outcomes.

This study encountered several limitations. The first was that, by definition, this outreach strategy does not reach those individuals who are not served by Deaf-friendly ministries. Thus, this strategy should be considered in conjunction with other information dissemination strategies. The second limitation was the lack of religious diversity among the participating ministries. While some Mormon temples and Jewish synagogues were identified, no Hindu or Muslim Deaf-friendly ministries were identified. This was in spite of using additional contact strategies, such as asking Deaf ethnic organizations and non-Deaf serving ministries for helping finding Deaf-friendly ministries within their sect. Additional strategies are needed to find those Deaf-friendly ministries, or other outreach methods need to be considered to reach that component of the Deaf community.

Despite the limitations, this study shows the potential for meaningful partnerships between Deaf-friendly ministries and health promotion programs. This capacity could expand as new Deaf-friendly ministries are identified and training materials are developed. Further research and enrichment trainings can help to expand the potential of this collaboration. Additionally, further study is required to evaluate long-term retention among the participating Deaf-friendly ministries and to determine the impact of incentives on participation and retention rates.

Conclusion

The Deaf community faces many of the same barriers to accessing cancer information and care as other minority groups. With limited health information available in ASL, it is crucial that all available resources are widely disseminated. Deaf-friendly ministries hold great promise for cost, effectively increasing the Deaf community's access to health promoting information and care and other social justice issues. The network of Deaf-friendly ministries has the potential to become a national partner in the infrastructure for promoting increased health literacy and health.

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