

Deaf Community Analysis for Health Education Priorities

Elaine G. Jones, Ralph Renger and Rob Firestone

ABSTRACT Deaf persons' access to health-related information is limited by barriers to spoken or written language: they cannot overhear information; they have limited access to television, radio, and other channels for public information; and the average reading level of Deaf adults is at a 3rd to 4th grade level. However, literature searches revealed no published reports of community analysis focusing specifically on health education priorities for Deaf communities. A seven-step community analysis was conducted to learn the health education priorities in Arizona Deaf communities and to inform development of culturally relevant health education interventions in Deaf communities. The word Deaf is capitalized to reflect the cultural perspective of the Deaf community. A 14-member Deaf Health Committee collected data using multimethods that included review of state census data, review of national health priorities, key informant interviews, discussions with key community groups, a mail survey ($n=20$), and semistructured interviews conducted in sign language with 111 Deaf adults. The community diagnosis with highest priority for health education was vulnerability to cardiovascular disease (CVD). Following completion of the community analysis, a heart-health education intervention (The Deaf Heart Health Intervention) was developed using a train-the-trainer, community health worker model. If this model proves to be effective in addressing vulnerability to CVD, then a similar protocol could be employed to address other health concerns identified in the Deaf community analysis.

Key words: cardiovascular disease, community analysis, Deaf, health education.

A community analysis was conducted to learn the health education priorities in Arizona Deaf communities. The term "Deaf" refers to a sociocultural subgroup of more than 2 million Americans who were significantly hearing-impaired at an early age, communicate primarily through sign language in adulthood, and participate in Deaf communities. The shared language, American Sign Language (ASL), and the culture of Deaf community members both unite them as a unique linguistic minority and separate them from the hearing world.

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Deaf persons' access to health-related information is limited by barriers to spoken or written language: they cannot overhear information; they have limited access to television, radio, and other channels for public information; and the average reading level of Deaf adults is at a 3rd to 4th grade level (Allen, 1994; Holt, 1994). Not surprising therefore are the published accounts of misinformation and misunderstanding among Deaf adults about basic health topics and behaviors, often concluding with calls for improved health education for this group (Anderson & Fox, 1988; Peinkofer, 1994). In addition, Healthy People 2010-documented objectives include eliminating marked health disparities between people with disabilities and people without disabilities. However, literature searches revealed no published reports of community analysis focusing specifically on health education priorities for Deaf communities.

Effective interventions to address vulnerability to poor health outcomes in communities must be grounded in community analysis to learn health education priorities of community members themselves.

The goal of this focused community analysis was to arrive at consensus with researchers and Deaf communities about health education priorities for Deaf communities. A second objective was to explore Deaf adults' preferences for the design and delivery of health education interventions for the health education priority identified as an outcome of the community analysis process. Discussion of results related to the second objective will be presented elsewhere.

The community analysis was guided by Reece's (1998) seven-step community analysis process: (a) identify the community or target group; (b) establish the purpose of the assessment; (c) determine the scope of the assessment; (d) gather data on the community or target group by defining the community, the people, and the health issues of concern; (e) analyze the data; (f) validate the findings; and (g) develop a community diagnosis.

Step 1: Identify the community or target group

The target group was the community of Deaf adults in the Tucson and Phoenix metropolitan areas. We did not target the population of adults who became hard-of-hearing at later ages ("late-deafened adults") and who communicate primarily through oral and aural means. Members of Deaf communities and late-deafened adults share the sensory experience of auditory deficits, and some of the communication barriers are similar. However, the social networks, educational backgrounds, life ways, and linguistic characteristics are distinctly different.

As with many sociocultural groups, the Deaf community is built on a defined intracultural social organization (Dolnick, 1993; Padden & Humphries, 1988). From the perspective of Deaf community members, a person holds greater or lesser status depending on factors such as whether one had Deaf or hearing parents (Deaf parents rate higher), where one attended grade school (residential school is better than mainstream), college education (Gallaudet accords highest status), ASL skills (fluidity and gracefulness rate high), and participation in Deaf community events (frequent participation suggests loyalty; absence may suggest disloyalty).

Deaf communities fit definitions of vulnerable populations as social groups who have increased

risk or susceptibility to adverse health outcomes (Flaskerud, 1998; Flaskerud & Winslow, 1998). Deafness occurs across ethnic groups, and hence, many Deaf community members are also members of ethnic minorities. The mean educational level and income for Deaf adults is significantly lower than that of the hearing population (McCrone, 1990), and 20–35% of Deaf or hard-of-hearing persons have a secondary disability (Allen, 1994) such as cerebral palsy or visual impairment. The combination of communication barriers, low income, limited education, secondary disabilities, and membership in ethnic minority groups put Deaf community members at increased risk of adverse health outcomes (Adler, Marmot, McEwen, & Stewart, 1999; Feinstein, 1993; Smith, 1999).

Step 2: Establish the purpose of the assessment

A multidisciplinary coalition was formed to develop plans for a community analysis (Badger, Gagan, & McNiece, 2001) focused on health education priorities in the Deaf community. This structure, self-named as the Deaf Health Committee (DHC), was consistent with a community development approach, emphasizing direct participation of community members in a grassroots or "bottom-up" decision-making process (Rissel & Bracht, 1999). The 14 members of the DHC included 5 Deaf (lay) community members, 2 Deaf professionals, 2 hearing professionals fluent in sign language, 1 hearing public health nurse, 1 hearing cardiac rehabilitation nurse, 1 hearing faculty member from the College of Public Health, 1 hearing graduate student from the College of Public Health, and 1 hearing faculty member from the College of Nursing. The DHC met multiple times to discuss strategies for identifying health education priorities, the role of the DHC members in the community analysis, national health priorities, personal knowledge about health problems in the local Deaf community, and health education delivery models, e.g., community health advisors and community-based classes (Eng, Parker, & Harlan, 1997; Farquhar et al., 1990).

Step 3: Determine the scope of the assessment

The scope of this community analysis was limited to adult members of the Tucson and Phoenix Deaf communities and focused specifically on health concerns and health education priorities. The DHC also discussed the time frame for the community assessment and the funding available to conduct the analysis. One year of funding was provided by the Arizona Disease Control Research Commission (Contract 5005), with the first 6 months for conducting the community analysis and the second 6 months to develop an intervention based on results of the community analysis.

Step 4: Gathering data

Health Issues of Concern to Deaf Community Members

This step involved gathering data on the community by defining the community, the people, and the health issues of concern. These data were gathered through both qualitative and quantitative methods, including review of Arizona census data, review of national health priorities, key informant interviews, discussions with key community groups, a mail survey ($n = 20$), and semistructured interviews with 111 Deaf community members.

Defining the Community and People

There were no data available specifically about the demographic characteristics of the targeted population. Therefore, estimates were derived from available information about the general Tucson and Phoenix populations and knowledge of the incidence of Deafness. According to Gallaudet Research Institute (1999), one quarter of 1% of the U.S. population is unable to hear and understand any speech, and is considered Deaf. Applying Gallaudet's estimate of the incidence of Deafness to the Tucson and Phoenix populations, we estimated that there were 2,103 Deaf adults in the Tucson area and 6,867 Deaf adults in the Phoenix area. This estimate may be low, as many graduates from Arizona's state school for Deaf children in Tucson and graduates of Phoenix day school for Deaf children continue to live in Tucson and Phoenix after graduation from high school, leading to a larger than expected concentration of Deaf community members in the two cities.

We assumed, for purposes of our analysis, that the ethnicity of the Deaf community would be similar to that of the surrounding community.

Health Issues of Concern

The DHC planned meetings with key informants (individuals and groups) within the Deaf community which represented ethnic, gender, and educational diversity and with people consistently identified as leaders in their communities. Members of the DHC met with the Community Outreach Program for the Deaf (COPD) Board of Directors (all Deaf), staff from Valley Center for the Deaf in Phoenix, and Deaf consumers. These individuals were active in a number of formal and informal Deaf organizations and well connected in their communities. These individuals and groups were invited to discuss health education priorities in the Deaf community.

The discussions confirmed the difficulties reported in the literature and the personal experience of the Deaf members of the DHC regarding barriers encountered by Deaf adults in obtaining accurate health information from hearing health professionals, the misinformation obtained from one another in the Deaf community, and the consequences of these problems. These discussions provided strong support for culturally relevant interventions to improve health education in Arizona's Deaf community.

The DHC sought additional input in two phases. In Phase I, data was solicited through a survey published in the monthly newsletter of Tucson's COPD. The survey questions corresponded with 15 health topics included in the Northern Illinois University Health Education Curriculum for traditionally underserved people who are deaf (Burgess, Shaw, Larew, Ouelette, & Long, 1990). Readers were asked to rate 15 health topics on a scale of 1–4, with 1 for “very important” and 4 used to indicate “not important.” Twenty surveys were returned, representing a 10% return rate (untabled). The topic with the highest rating was “Heart disease: what is it, and how to prevent it,” second was “Cancer: self test and warning signs,” followed by a three-way tie for third rank between “Mental health: stress, warning signs, ways to help”; “Sex information, safe sex, and sex disease—HIV/AIDS”; and “Substance use and abuse—alcohol and drugs”; and finally a two-way tie for fourth between “Dental care” and “Nutrition.”

At this point, the DHC noted that the results of the mail survey and opinions of key informants were consistent with the experiences of Deaf members of the DHC and the observations of professional members of DHC who worked with Deaf clients, and supported heart health education as a first priority. However, the small number of returned surveys was disappointing, and there were concerns about the use of a written English mail survey, given the limited English skills of many Deaf adults. Therefore, the DHC implemented Phase II to collect data from a wider sample of the Deaf community about their general health education priorities (Table 1) and additional questions specific to CVD-risk factors (untabled).

The DHC agreed that the most valid way to collect these data from Deaf adults with diverse language and education levels was through individual interviews conducted in sign language by trained data collectors who were fluent in ASL. Two interview guides were developed by the DHC through an iterative process: *A General Health Interview* and *A Heart Health Risk Interview* with separate forms for men and women.

The *General Health Interview Guide* was based on a questionnaire used by the Pima County Health Department for initial contacts with clients and families. The interview solicited general demographic information and participants' opinions about health concerns in their community. The questionnaire was adapted for use with the Deaf community by specifying that questions referred to the Deaf community, rather than the general community.

TABLE 1. Results of Data Collected in Phase II Regarding Perceived Health Problems in the Deaf Community

Phase II: Semistructured Interviews (n = 111)	
Health Problem	Number and Percent
Drug abuse	51 (46)
High blood pressure	51 (46)
Alcoholism	50 (45)
Diabetes	41 (37)
Cancer	40 (36)
Arthritis	35 (32)
AIDS/HIV	28 (25)
Mental health	27 (24)
Child abuse	27 (24)
Nutrition	24 (22)

Note. Results of Phase I Newsletter Survey and Phase II Heart Health Risk Interviews are presented in the text.

Each participant was presented with a list of 24 health problems and asked whether they considered these to be health concerns in their Deaf community. Respondents were not limited in how many of the health problems they could name as problems in their community.

The *Heart Health Risk Interview* was devised in consultation with an experienced cardiac rehabilitation nurse, through review of the American Heart Association materials, discussions with the DHC, and review of addition literature regarding CVD-risk factors (American Heart Association, 2002; Grundy, 1997; Kingsbury, 1998). The DHC reviewed a number of existing assessment tools for CVD risk for possible use with Deaf adults. However, the DHC believed that they were unsuitable for use with Deaf adults because the English level was too high, the vocabulary unfamiliar, the format confusing, or it was too long. The *Heart Health Risk Interview* included two versions, one for men and one for women. Both versions contained questions about modifiable and nonmodifiable risk factors of CVD (American Heart Association, 2002; Grundy, 1997; Kingsbury, 1998): age, family history of CVD, smoking status, blood pressure, exercise habits, cholesterol levels, eating habits, height and weight [for body mass index (BMI)], diabetes, perceived stress, depression, and personal history of CVD. It was anticipated that many Deaf adults might not know their cholesterol levels, and hence, the interview guide included questions about eating patterns as an alternate means for assessing participants' risk for elevated cholesterol levels. This was accomplished by presenting each person with sample menus of low fat, moderate fat, and high fat diets (an innovation of the DHC committee) and asking them to decide which was most similar to their own eating habits. The women's version of the *Heart Health Risk Interview* also queried about hormone status. The belief was that more accurate information from participants would be forthcoming if we collected data individually during personal interviews rather than using existing written English assessment tools. The interview guides were pilot-tested with three trained, Deaf adult volunteers; final revisions were made and approved by the DHC. The project was then submitted to and approved by the University of Arizona Institutional Review Board for Human Subjects Protection.

The interviews were conducted by six trained staff who were fluent in sign language. Training included review of the questions, discussion about how to sign specific terms, and agreement about a necessary degree of flexibility on choosing sign vocabulary appropriate to the participants' background. Emphasis was also placed on limiting the amount of explanation permitted. There was a commitment to making questions understood to the participants, but data collectors were reminded about the purpose of the interviews and encouraged not to engage in health teaching during the interviews. Four data collectors were Deaf themselves (two women and two men), and two were hearing women who were professional sign language interpreters who had worked with the Deaf community for many years.

The interviewers began by explaining the project to the potential participants in ASL. If the person agreed to participate, the data collector interpreted the semistructured interview questions from written English into ASL for each participant, interpreted the respondent's answers from ASL into English, and recorded the responses in English on the interview guides. Each participant was assigned a number, and names did not appear on the data collection forms.

There was a concern that some respondents might not understand the survey questions because of low educational levels and limited understanding of English vocabulary, despite presenting the questions in ASL. For example, it is essential to ask about a person's cholesterol levels in interviews about risk of CVD. However, there is no ASL sign for "cholesterol," and hence, it must be finger spelled. Hence, even if the question is presented in ASL, the individual may not be able to answer if he or she does not know what the finger spelled word "cholesterol" means. To assess this concern, we asked the interviewers to rate how confident they were on a scale of 1–5 that the respondent understood all the questions, and participants themselves were asked to indicate how well they understood the questions. Higher scores indicated greater confidence that the questions were understood by the participant.

Step 5: Analyzing the data

This section presents the results of analysis of data obtained in Phase II from the *General Health Inter-*

view (Table 1) and the *Heart Health Risk Interview* (untabled). First, the sample characteristics are presented followed by data about modifiable and nonmodifiable CVD-risk factors among interview participants.

Participants in Semistructured Interviews

The sampling plan was to recruit at least 1% ($n = 90$) of the estimated number of Deaf adults in the Tucson and Phoenix areas, with equal numbers of men and women participants with a range of educational and income levels, a broad age range, and with an ethnic composition reflecting the surrounding community (Hautman & Bomar, 1995). The sample was recruited through personal contacts and at events for Deaf adults in both Tucson and Phoenix Arizona over a period of 4 months, using a community network strategy (Welshimer, 1995). The final sample consisted of 111 Deaf men and women (Table 2), and the ethnic composition of interview participants closely mirrored the ethnic composition of the general Tucson and Phoenix population (Population Statistics Unit, 1998).

The PI reviewed interview forms used in data collection for missing data. Reasons for missing data were discussed with the data collectors and noted on the original interview forms. The mean scores among the interviewers about how confident they were that the participants understood the interview questions was 4.3 on a 5-point Likert scale, with higher scores indicating greater confidence. The mean self-rating score for understanding among participants was 4.6 on the same scale, with higher scores indicating better understanding. Data analysis was limited to descriptive data, with frequencies and percentages calculated for answers to each interview question.

The Heart Health Risk Interview

Fifty-five percent of interview participants reported a family history of cardiac events among first-degree relatives, and said that 20% of those events had occurred when the family member was less than 55 years old. The great majority (91%) of participants said that they had no personal history of cardiac events. Only eight persons had diabetes, with three of these diagnosed with diabetes before age 40. Nearly a third (28%) did not know whether their blood pressure was normal: 45% thought that they

TABLE 2. *Demographic Characteristics—Phase II Sample (n = 111) of Deaf Adults*

Demographic Variable	Number and Percent
Gender	
Men	42 (38)
Women	69 (62)
Age (years)	
18–34	16 (15)
35–44	37 (33)
45–54	16 (14)
Over 54	42 (38)
Education	
Grade school	11 (10)
High school/GED	54 (49)
Some college/vocational	23 (21)
College graduate	19 (17)
Unreported	4 (3)
Marital Status	
Married	41 (38)
Single	43 (37)
Widowed	6 (5)
Divorced	18 (17)
Other	3 (3)
Ethnicity	
White/non-Hispanic	71 (64)
Hispanic	25 (23)
Native American	7 (6)
African American	4 (3)
Asian/Pacific Islander	1 (1)
Other	3 (3)
Annual income categories	
Under \$5,000	12 (11)
\$5,000–9,999	20 (18)
\$10,000–19,999	22 (20)
\$20,000–29,999	16 (14)
\$30,000–39,999	10 (9)
\$40,000–49,999	3 (3)
Over \$50,000	2 (2)
Unreported	26 (23)

had normal blood pressure, 20% said that their blood pressure was borderline (between 140/90 and 160/95), and 7% said that they had high blood pressure (over 160/95). We could not determine the hormonal status of the majority of women in the sample, as more than half declined to respond to questions regarding hormonal status.

Questions about modifiable CVD-risk factors included questions about cholesterol levels, eating patterns, height and weight (for calculating BMI), exercise habits, experience of stress and depression, and smoking habits. The majority of our sample (82%) thought that their cholesterol levels were under 200. However, the interviewers were not con-

fidant that the participants were accurate in their reported cholesterol levels. Rather, the interviewers believed that many Deaf adults interviewed either did not know what “cholesterol” was, or were unaware of having it checked, or assumed that their cholesterol was fine, because no one had told them differently.

Nearly half (49%) considered their diets as most similar to the sample menus that were moderate to high fat. Using self-reported weights and heights, 43% of the total sample was found to be overweight with a BMI >25 kg/m². Among the men, 26% were overweight and 13% were obese. Among the women, 25% were overweight and 30% were obese.

Most survey respondents (54%) exercised less than 3 times each week. In response to questions about how often they had felt angry or frustrated over the last month, half (50%) checked “some of the time” and 13% checked “most of the time.” Fewer survey respondents indicated that they had felt depressed either some (31%) or most (13%) of the time during the past month. Only 15% of our sample reported that they were current smokers.

Step 6: Validating the findings

Results of the community analysis were presented to the staff and Board of Directors for Tucson's COPD and Phoenix's Valley Center for the Deaf. Discussions centered on validating our findings with members of the Deaf community, coming to a decision about which health problem should be our first priority for a health education intervention, and exploring options for delivering a health education intervention. The findings “rang true” to these groups. Naturally, there was reluctance to select just one area, as there was ongoing concern about all the health concerns identified in the community analysis. Consensus was that initial efforts would be in primary prevention of heart disease through health education intervention about nutrition, physical activity/exercise, stress and stress management, and smoking cessation. By focusing on these areas, additional health concerns such as diabetes (nutrition and weight loss), lung cancer (smoking cessation), and mental health concerns (stress management) would be addressed as well.

Step 7: A community diagnosis

Our community diagnosis with highest priority for our first health education intervention was:

vulnerability to cardiovascular disease in Arizona's Deaf communities related to modifiable cardiovascular disease risk factors as manifested by moderate-to-high fat diets, overweight and obesity, lack of knowledge about blood cholesterol levels, inadequate exercise, reports of frequent feelings of stress and depression, and smoking.

Conclusion

Following completion of the community analysis, a heart-health education intervention, The Deaf Heart Health Intervention (DHHI), was developed using a train-the-trainer, community health worker model. The DHHI is an 8-week intervention with classroom activities and home assignments. The theoretical foundation is social cognitive theory, informed by research regarding Deaf adults' preferred teaching–learning strategies and knowledge about Deaf cultural lifeways. Measures to evaluate the DHHI (Table 3) were translated into ASL, recorded on videotape, and field-tested prior to use with the DHHI or adapted for use with Deaf adults. The DHHI is being pilot-tested using a quasi-experimental, two-group study design (funded by the National Institute of Nursing Research 1-R15 AG16192-01). If this model proves to be both feasible and effective in addressing vulnerability to CVD, then a similar protocol could be employed to address other health concerns identified in the Deaf community analysis.

This community analysis was conducted to learn the health education priorities in Arizona Deaf

communities and to inform development of culturally relevant health education interventions in Deaf communities. Strengths of the community analysis included collaboration of Deaf community members and members of health-related disciplines in designing and conducting the community analysis, data collection through interviews in sign language, and interview participants whose ethnicity reflected the ethnic composition of the surrounding community. Limitations included use of interview guides with limited pilot-testing and reliance on self-reports.

Results of the community analysis demonstrated numerous health-related concerns in Deaf communities and identified CVD-risk factors among the interview participants. Our vision is that multiethnic Deaf communities across the nation will have the capacity for sustained health promotion/risk reduction programs, including those related to heart health (Courtney, Ballard, Fauvery, Garota, & Holland, 1996).

Public health nurses have been leaders in health education and primary prevention among vulnerable populations throughout history. The experience and perspective of public health nurses are key to the success of collaborative efforts with other health professionals and with members of Deaf communities to decrease vulnerability to poor health outcomes among Deaf adults.

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TABLE 3. *Dependent Variables and Measures Used in Pilot-Testing the Deaf Heart Health Intervention (DHHI) (Jones, 2003–2005)*

Dependent Variable	Measure
Self-efficacy for nutrition, physical activity, and stress	Self-rated abilities for health practices scale (Stuifbergen & Becker, 1994)
Self-efficacy for smoking cessation	Smoking self-efficacy (Velicer, Prochaska, Rossi, & Snow, 1992)
Nutrition knowledge	General nutrition questionnaire (Parmenter & Wardle, 1999)
Eating patterns	Analysis of 3-day eating diary (Using Food Processor, EQL, esha research)
Physical activity	Physical activity record (7 days) (Sallis, Haskell, & Wood, 1985)
Perceived stress	Perceived stress scale (Cohen, Kessler, & Gordon, 1995)
Smoking cessation	7-day point prevalence report

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