Original Report

Young Deaf Adults' Knowledge of Human Papillomavirus and Human Papillomavirus Vaccine's Effectiveness in Preventing Cervical, Anal, Penile, and Oral Cancer

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A B S T R A C T

Study Objective: To describe knowledge and risk perception of human papillomavirus (HPV) among deaf adults who use American sign language (ASL) comparison with hearing adults in the United States.
Design: Secondary HPV knowledge data for the deaf subset sample were drawn from the Health Information National Trends survey in ASL that was administered between 2015 and 2018. HPV knowledge data for the hearing subset sample were drawn from cycle 5 of the Health Information National Trends survey in English that was administered in 2017.
Setting: Surveys are a nationally based survey of deaf ASL users in the United States and a nationally based survey of hearing non-ASL users in the United States.
Participants: The age of the deaf and hearing subset samples was determined on the basis of catchup vaccine eligibility criteria as outlined by the Centers for Disease Control and Prevention that recommends catchup vaccination in women, men who have sex with men, immunocompromised individuals, and those who identify as transgender.
Interventions and Main Outcome Measures: We examined HPV, HPV vaccine, and HPV-related cancer knowledge in deaf and hearing subsets.
Results: Our sample consisted of 235 deaf and 115 hearing adults aged 18-26 years. Of the deaf participants 58% (136/235) reported knowledge of HPV compared with 84% (97/115) of hearing participants ($P < .001$). Hearing participants showed higher accuracy in risk perception of HPV relation to cervical cancer compared with deaf participants ($P < .001$). Hearing participants were more likely to have heard of the HPV vaccine as well as believe it is successful in preventing cervical cancer compared with deaf participants ($P < .001$).
Conclusion: Deaf ASL users are less likely to have knowledge of HPV, virus-related cancer risk, and preventative vaccination compared with hearing peers.
Key Words: Human papillomavirus, Cancer, Vaccine, Deaf, Hard of hearing, Deafness, American sign language, Young adults

Introduction

In the United States there are estimated to be 250,000-500,000 deaf adults who use American sign language (ASL) as their primary language.[1] For these patients, there are unique linguistic-, cultural-, and communication-related barriers to health literacy that place deaf individuals at risk for inadequate knowledge of health-related topics and risk factors for disease including lack of proficiency in written English, limited access to mass media, and poor communication with medical providers.[2,3] As a result, significant health disparities and knowledge gaps exist for this population that have been shown to result in poor health outcomes.[4–6]

One possible area of disparity for deaf ASL users is in their understanding of human papillomavirus (HPV)-related knowledge. HPV is a sexually transmitted virus that has the potential to cause cervical, anal, and oral cancers, which are diagnosed at a rate of approximately 30,000 per year.[7] A series of vaccines is available to prevent transmission of HPV and consequently these types of cancer, and is recommended for girls and boys aged 11-12 years with catchup vaccination routinely recommended for all young men through age 21 years, and young men in high-risk categories such as those who are immunocompromised or identify as having sex with men, women, and transgender adults through age 26 years.[8] Men aged 22 to 26 years who wish to have protection and are not previously immunized may receive the vaccination. Despite these recommendations, endorsed by the Centers for Disease Control and Prevention and other professional medical organizations, national completed vaccination rates estimated in 2017 were reported to be only 66% for adolescents.[9] Although addressing parental perception and knowledge of HPV is critical in the effort to improve vaccination rates, because vaccines are recommended to be given during childhood, not all young adults have been vaccinated themselves and might still be eligible for the vaccine, remain at risk for contracting HPV, and are beginning routine HPV-related cancer screening. As a result, young adults remain an important target for HPV education. In studies of college students in the United States, many had heard of HPV but did not perceive themselves as being at risk for contracting HPV.[10,11] To better understand these discrepancies, Nelson and colleagues developed the Health Information National Trends Survey (HINTS) to collect data about the American public's use of

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cancer-related information including awareness of HPV and understanding of causal relationships between HPV and cervical, anal, penile, and oral cancers.[12]

HPV knoweldge data collected through HINTS and other sexual health surveys have shown disparities related to race, use of an interpreter for non-English speaking patients, insurance status and higher education in the general population. However, it is not reported if disparities exist for deaf ASL users nor is it known how severe that knowledge gap might be.[13–15] Ideally, with directed ASL-based interventions to improve awareness and understanding of HPV, deaf ASL users will have increased rates of preventative vaccination given the known positive association between provider ASL use and deaf patients seeking of preventive services.[3,4]

Our study used secondary data from an accessible national health survey in ASL and English (HINTS-ASL[16]) to evaluate deaf young adults' knowledge of HPV, and understanding of the HPV vaccine's effectiveness in preventing different types of cancer. We hypothesized that deaf young adults' level of knowledge about these issues would be significantly lower than that of hearing young adults.

Materials and Methods

Secondary HPV knowledge data for the deaf subset sample (18-26 years old) were drawn from the Health Information National Trends survey in ASL that was administered between 2015 and 2018.[16] HPV knowledge data for the hearing subset sample (18-26 years old) were drawn from the HINTS 5, cycle 1, public data set using a nationally representative survey that was administered in 2017.[12] The age of this subset sample was determined on the basis of catchup vaccine eligibility criteria as outlined by the Centers for Disease Control and Prevention that recommends catchup vaccination in women, men who have sex with men, immunocompromised individuals, and those who identify as transgender between the ages of 18 and 26 years, and men between the ages of 18 and 21 years.[8] Men aged 22-26 who wish to have protection and are not previously immunized may also receive the vaccination.

For the purpose of the current study, the hearing data set included respondents who had no hearing difficulties and used English as their primary language. We did not gather information on HPV vaccine uptake. Questions used in this study included those on topics in the following sections.

HPV Knowledge

Deaf and hearing participants were asked a series of questions related to whether they had heard of HPV, understood what HPV stood for, and whether it can cause cervical, penile, anal, or oral cancers. Additional questions also included regarding whether HPV is a sexually transmitted disease and whether it requires medical treatment or will resolve on its own without treatment.

(1) Have you ever heard of HPV? HPV stands for human papillomavirus. It is not HIV, herpes simplex virus, or herpes.

(2) Do you think that HPV…
   (a) can cause cervical cancer?
   (b) can cause penile cancer?
   (c) can cause anal cancer?
   (d) can cause oral cancer?
   (e) is a sexually transmitted disease?
   (f) requires medical treatment or will it usually go away on its own without treatment?

HPV Vaccination

Three questions were used to gather information about the deaf or hearing person's awareness of HPV vaccine and its perceived effectiveness in preventing cervical cancer and, for those within the recommended age range, whether the doctor had discussed with them about the HPV shot or vaccine:

(1) A vaccine to prevent HPV infection is available and is called the HPV shot, cervical cancer vaccine, Gardasil (Merck Sharp & Dohme Corp), or Cervarix (GlaxoSmithKline). Before today, have you ever heard of the cervical cancer vaccine or HPV shot?
(2) In your opinion, how successful is the HPV vaccine at preventing cervical cancer?
(3) In the past 12 months, has a doctor or health care professional ever talked with you or an immediate family member about the HPV shot or vaccine?

Patient–Physician Communication

Deaf respondents were asked to select a communication mode that they used most frequently with the health care professional that they saw the most. Response options used for this study included: (1) using ASL directly or through interpreter; and (2) speaking/speechreading/writing. For patient-centered communication (PCC), the following question was presented to deaf and hearing participants: How often did the doctors, nurses, or other health care professionals you saw during the past 12 months do each of the following:

(1) Give you the chance to ask all of the health-related questions you had?
(2) Give the attention you needed to your feelings and emotions?
(3) Involve you in decisions about your health care as much as you wanted?
(4) Make sure you understood the things you needed to do to take care of your health?
(5) Help you deal with feelings of uncertainty about your health or health care?

Responses (never [1] to always [5]) to each item were scored, averaged, and linearly transformed to a scale score.

Statistical Analyses

Descriptive statistics, including percentages and cross-tabulations, were used to summarize the sample characteristics of respondents who were vaccine-eligible (aged

Table 1
Sociodemographic Characteristics of Deaf Vaccine Age-Eligible Participants According to HPV Awareness

Characteristic		Deaf Young Adults				
		Heard of HPV (n = 138)		Had Not Heard of HPV (n = 98)		*P*
		Mean (SD)		Mean (SD)		
Age, years		23 (2.2)		22 (2.4)		<**.01**
BMI		26 (6.6)		26 (6.8)		.42
PCC		62 (23.7)		59 (26.7)		.19
	Subgroups	n	%	n	%	
Gender						<**.01**
	Male	49	35.5	53	54.1	
	Female	89	64.5	45	45.9	
	Missing	0		0		
Race						.96
	White	76	55.1	56	57.1	
	Black	17	12.3	14	14.3	
	Asian	4	2.9	2	2.0	
	Hispanic	30	21.7	20	20.4	
	Other	11	8.0	6	6.1	
	Missing	0		0		
Occupation						<**.05**
	Employed	55	40.1	29	29.6	
	Unemployed	12	8.8	18	18.4	
	Student	69	50.4	47	48.0	
	Other	1	0.7	4	4.1	
	Missing	1		0		
Education						<**.01**
	High school	17	12.5	30	31.3	
	Some college	59	43.4	40	41.7	
	College	60	44.1	26	27.1	
	Missing	2		2		
Health Status						.24
	Poor/fair	17	12.3	14	14.3	
	Good	40	29.0	19	19.4	
	Very good/excellent	81	58.7	65	66.3	
	Missing	0		0		
Family history of cancer						.1.72
	None	28	20.7	23	23.5	
	Have history	93	68.9	60	61.2	
	Not sure	14	10.4	15	15.3	
	Missing	3		0		
Personal history of cancer						.15
	None	132	97.8	97	99.0	
	Have or had cancer	3	2.2	1	1.0	
	Missing	3		0		
Parent hearing status						.31
	Deaf	64	47.4	39	40.6	
	Hearing	71	52.6	57	59.4	
	Missing	0		2		
Health insurance						.06
	Yes	130	94.9	88	89.8	
	No/not sure	7	5.1	10	10.2	
	Missing	1		1		
Regular provider						.72
	Yes	70	50.7	47	48.0	
	No	68	49.3	51	52.0	
	Missing	0		0		
Communication modality with health care provider						.68
	ASL (direct or interpreter)	74	56.1	45	48.4	
	English (written/lipreading/other)	58	43.9	48	51.6	
	Missing	6		5		

Bolded values indicates significant *P*-values.
ASL, American sign language; BMI, body mass index; PCC, patient-centered communication.

18-26 years old). χ^2 Tests were also used to describe differences in HPV knowledge and perceived risk of HPV for different types of cancer across hearing status. *t* Tests were used to describe differences across age, body mass index, and PCC. The statistical program SPSS version 25.0 (IBM Corp) was used for all analyses. Gallaudet University's institutional review board approved the study.

Results

Sample Description

A total of 235 deaf and 115 hearing adults aged 18-26 years answered all HPV-related questions about whether they had heard of the virus and how successful they believed the HPV vaccine to be at preventing cervical

Table 2
Sociodemographic Characteristics of Hearing Vaccine Age-Eligible Participants According to HPV Awareness

Characteristic		Hearing Young Adults				
		Heard of HPV (n = 97)		Had Not Heard of HPV (n = 21)		*P*
		Mean (SD)		Mean (SD)		
Age, years		23 (2.2)		22 (2.3)		**<.01**
BMI		25 (5.7)		26 (4.9)		.55
PCC		76 (24.3)		87 (17.8)		.06
	Subgroups	n	%	n	%	
Gender						**<.05**
	Male	33	34.0	12	57.1	
	Female	64	66.0	9	42.9	
	Missing	0		0		
Race						.76
	White	41	43.2	11	55.0	
	Black	10	10.5	3	15.0	
	Asian	7	7.4	1	5.0	
	Hispanic	31	32.6	4	20.0	
	Other	6	6.3	1	5.0	
	Missing	2		1		
Occupation						.25
	Employed	58	61.7	9	45.0	
	Unemployed	7	7.4	4	20.0	
	Student	27	28.7	34	29.8	
	Other	2	2.2	0	0.0	
	Missing	3		1		
Education						.18
	High school	16	16.7	6	28.6	
	Some college	27	28.1	8	38.1	
	College	53	55.2	7	33.3	
	Missing	1		0		
Health Status						.63
	Poor/fair	8	8.2	3	14.3	
	Good	24	24.7	4	19.0	
	Very good/excellent	65	67	14	66.6	
	Missing	0		0		
Family history of cancer						.18
	None	23	24.0	9	42.9	
	Have history	62	64.6	11	52.4	
	Not sure	11	11.5	1	4.8	
	Missing	1		0		
Personal history of cancer						–
	None	97	100	21	100	
	Have or had cancer	0	0	0	0	
	Missing	0		0		
Health insurance						.40
	Yes	88	91.7	18	85.7	
	No/Not Sure	8	8.3	3	14.3	
	Missing	1		0		
Regular provider						.95
	Yes	45	46.9	10	47.6	
	No	51	53.1	11	52.4	
	Missing	1		0		

Bolded values indicates significant *P*-values.
BMI, body mass index; PCC, patient-centered communication.

cancer. Approximately 45% (106/235) of the deaf sample had deaf parents. Within each sample, 138 (58%) deaf and 97 (84%) hearing participants had heard of HPV ($P < .001$).

As shown in Table 1, within the deaf sample, significantly more women (66%; 89/134) had heard of HPV compared with 48% (49/102) of male participants. Most of the deaf respondents who had heard of HPV were employed and had a college degree. No significant differences emerged across HPV awareness for health indicators such as regular provider, communication modality used with providers, or general health. Furthermore, having a personal or family history of cancer did not differ for HPV awareness within the deaf sample. Similar findings regarding the lack of personal or family history of cancer effect on HPV awareness were observed for the hearing young adult sample (Table 2).

Table 3 shows a summary of the demographic data for deaf and hearing age-eligible respondents who had heard of HPV. Although age, sex at birth, and race/ethnicity were similar for both groups, there were more participants who were current students in the deaf group (50%; 69/138) compared with the hearing group (29%; 27/97). Although no hearing status group differences emerged for personal history of cancer, the deaf group had significantly more participants who did not know if they had a family history of cancer ($P < .001$). Both groups did not significantly differ

Table 3
Sociodemographic Characteristics of Vaccine Age-Eligible Participants Who Have Heard of HPV

Characteristic		Group (18-26 years old; Heard of HPV)				
		Deaf (n = 138)		Hearing (n = 97)		*P*
		Mean (SD)		Mean (SD)		
Age, years		23 (2.2)		23 (2.2)		**<.05**
BMI		26 (6.7)		25 (5.7)		.22
PCC		62 (23.7)		76 (24.3)		**<.001**
	Subgroups	n	%	n	%	
Birth sex						.87
	Male	48	35.0	33	34.0	
	Female	89	65.0	64	66.0	
	Missing	1		0		
Race						.12
	White	76	55.5	41	43.2	
	Black	17	12.4	10	10.5	
	Asian	4	2.9	7	7.4	
	Hispanic	29	21.2	31	32.6	
	Other	11	8.0	6	6.3	
	Missing	0		2		
Occupation						**<.01**
	Employed	55	40.4	58	61.7	
	Unemployed	11	8.1	7	7.4	
	Student	69	50.7	27	28.7	
	Other	1	0.7	1	1.1	
	Missing	1		3		
Education						**.05**
	High school	17	12.6	16	16.7	
	Some college	59	43.7	27	28.1	
	College	59	43.7	53	55.2	
	Missing	2		1		
Health Status						.41
	Poor/Fair	17	12.4	8	8.2	
	Good	39	28.5	24	24.7	
	Very Good/Excellent	81	59.1	65	67.0	
	Missing	1		0		
Family history of cancer						.81
	None	28	20.9	23	24.0	
	Have history	92	68.7	62	64.6	
	Not sure	14	10.4	11	11.5	
	Missing	4		1		
Personal history of cancer						.14
	None	131	97.8	97	100.0	
	Have or had cancer	3	2.2	0	0.0	
	Missing	4		0		
Health insurance						.33
	Yes	129	94.9	88	91.7	
	No/not sure	7	5.1	8	8.3	
	Missing	2		1		
Regular provider						.60
	Yes	68	49.6	51	53.1	
	No	69	50.4	51	53.1	
	Missing	1		1		
Communication modality with health care provider						–
	ASL (direct or interpreter)	73	55.3	–	–	
	English (written/oral)	58	43.9	–	–	
	Other	1	0.8	–	–	
	Missing	6		–	–	

Bolded values indicates significant *P*-values.
ASL, American sign language; BMI, body mass index; PCC, patient-centered communication.

for health insurance coverage and regular provider; however, the hearing group rated their PCC experiences significantly higher than did the deaf group ($P < .001$).

Table 4 shows a comparison of HPV and cancer risk perception between deaf and hearing participants who were vaccine-eligible. Hearing participants showed significantly higher accuracy in their risk perception of HPV being linked to cervical cancer than did the deaf participants ($P < .001$). Hearing participants also were significantly more likely to have heard of the HPV vaccine ($P < .001$) and believe that the HPV vaccine was successful at preventing cervical cancer compared with deaf participants ($P < .01$). Both groups' risk perception for other types of cancer (penile, anal, oral) did not differ. Deaf and hearing participants reported similar rates of having had a discussion with a doctor or health care professional about the HPV vaccine.

Discussion

To our knowledge, this national study is the first to explore the knowledge and risk perceptions of deaf young adults regarding HPV, its infectious and neoplastic

Table 4
Risk Perception Among Vaccine Age-Eligible Participants Who Have Heard of HPV

Question	Deaf (n = 138)		Hearing (n = 97)		*P*
	n	%	n	%	
Do you think HPV can cause cervical cancer?					.001
No/not sure	73	53.3	21	22.1	
Yes	64	46.7	74	77.9	
Do you think HPV can cause penile cancer?					.09
No/not sure	109	79.6	65	69.9	
Yes	28	20.4	28	30.1	
Do you think HPV can cause anal cancer?					.39
No/not sure	114	83.2	74	78.7	
Yes	23	16.8	20	21.3	
Do you think HPV can cause oral cancer?					.19
No/not sure	109	79.6	67	72.0	
Yes	28	20.4	26	28.0	
Do you think HPV is a sexually transmitted disease?					.13
No/not sure	59	43.1	29	30.2	
Yes	78	56.9	67	69.8	
Do you think HPV requires medical treatment or will it usually go away its own without treatment?					**<.05**
Requires medical treatment	128	93.4	89	92.7	
Will usually go away on its own	9	6.6	7	7.3	
Before today, have you ever heard of the cervical cancer vaccine or HPV shot?					**<.001**
No	48	34.8	14	14.4	
Yes	90	65.2	83	85.6	
In your opinion, how successful is the HPV vaccine at preventing cervical cancer?					**<.01**
Not successful	94	68.1	49	51.0	
Successful	44	31.9	47	49.0	
In the past 12 months, has a doctor or health care professional ever talked with you or an immediate family member about the HPV shot or vaccine?					.61
No/not sure	81	71.1	58	67.4	
Yes	33	28.9	28	32.6	
In the past 12 months, has a doctor or health care professional recommended that you or someone in your immediate family get the HPV shot or vaccine?					.76
No/not sure	88	77.9	66	75.9	
Yes	25	22.1	21	24.1	

Bolded values indicates significant *P*-values.
HPV, human papillomavirus.

consequences, and the effect of vaccination on preventing HPV-related cancers. Our study supports the hypothesis that deaf young adults who use ASL, compared with hearing English-speaking members of the United States, were significantly less likely to believe that HPV can cause cervical cancer and to recognize the HPV vaccine's efficacy in reducing the risk of cervical cancer. Although both groups did not differ in their rates of discussing the vaccine with their doctors, the overall rates of discussions occurring was found to be low and is an area for potential improvement for all young adults. Another area for improvement across deaf and hearing young adult samples gleaned from this study is in the knowledge of HPV's relationship with penile, oral, and anal cancers because of the overall low risk perception scores related to these types of malignancies.

The disparity in deaf people's HPV knowledge and perceived effectiveness of the vaccine in reducing the risk of cervical cancer suggest some potential contributors to poor HPV knowledge. First, deaf respondents were more likely to be uncertain of any family history of cancer and therefore were unable to relay this to their doctor. This is consistent with challenges deaf people experience related to accessing all incidental family communication, and potentially health-related discussions, as a consequence of being born to hearing families who typically do not use ASL.[2] Second, because there was no significant difference between deaf and hearing young adults' participation in HPV-related discussion with their doctors, it might be concluded that although doctors do recognize the risk of HPV in both populations and are seeing these patients in their clinics, they are not equipped to appropriately counsel them. For this reason, it is possible that other populations at risk for poor physician–patient communication also have inadequate HPV-related funds of knowledge for similar reasons. This makes equitable access to information through a patient's primary language critical to improving overall understanding of HPV.

There were some limitations to this study. The higher proportion of students compared with those not currently enrolled in school, might influence our results in unknown ways because of the known effect of educational status on HPV-related knowledge.[13] The respondent population might not represent the general young adult population in terms of factors relevant to community health education, and we cannot extrapolate from our data to the HPV knowledge of young deaf children or teenagers who are also in need of HPV-related education. As of yet, we have no data on the actual vaccination rates or relationships between knowledge and actual vaccination practices of deaf adults in the United States.

By providing insight into the nature of the gaps in HPV-related knowledge for deaf young adults, our results suggest that there is a need for increased education surrounding HPV for this population. Potential areas for future research and intervention development include improving communication with providers through language concordance and professional interpreting services. It might also be beneficial to develop community based HPV-related health

education in culturally sensitive modalities that target deaf young adults. Deaf ASL-using parents who are responsible for the vaccinations of their children might also be an appropriate target population for interventions although they were not evaluated in this particular study. Moreover, it is possible that developing tools for translating health knowledge into linguistically concordant, culturally appropriate resources might benefit similar at-risk populations.

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